



DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) What role does social identity play in post-stroke psychological adjustment? ; 2) 'Don't carry the load on your own....' How staff members manage suicidal ideation and attempts in Older Adults ; 3) Investigating intrusive imagery, appraisals and positive mood states in Bipolar Disorder.

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Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology – Volume 1 of 2

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Doctorate in Clinical Psychology

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June 2016

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Abstracts

Critical Literature Review Abstract

Background Research into the psychological effects of stroke has developed into understanding the fluidity of psychological adjustment rather than distinct diagnostic categories of mental health conditions. Research indicates the role of identity change after stroke, however this is yet to be explored in-depth. A handful of empirical studies also highlight the role social groups and identity in adjustment and quality of life after stroke. **Purpose** To synthesise qualitative studies on identity after stroke, from stroke survivors' and caregivers' perspectives. To develop the understanding of the role of social identity in post-stroke psychological adjustment. **Methods** A systematic search of qualitative studies in peer reviewed journals from January 2000 to March 2016 was undertaken. The CASP (Critical Appraisal Skills Programme) was used to appraise the quality of selected studies. A synthesis was conducted using a meta-ethnographic approach (Noblit & Hare, 1988). Themes relating to identity and self were analysed in the synthesis. **Results** 25 studies were included in the meta-ethnography. The results of these papers fell into two themes; *Relationships with Self*, and *Social Relationships*. The relationship between the themes was considered using Social Identity Theory, developing a new post-stroke self as an adjustment process. **Conclusions** This synthesis indicates the relationship between the self, social relationships and social identity post-stroke and highlights the role of these factors in adjustment to life and the 'new self' after stroke. This presents a new direction for research into identity after stroke, and needs further exploration to apply this knowledge to interventions after stroke.

Main Research Project Abstract

Background Recent research indicates the role of intrusive images in Bipolar Disorder (BP). It is hypothesised that imagery is an important internal state in BP (Holmes et al, 2008). This has not yet been compared to a non-clinical population. However, it is also thought that the type of internal state (whether imagery, verbal thoughts, heart rate) does not matter, but the extreme, conflicting appraisals attached to the internal state (Mansell et al, 2006) which results in difficulties in mood regulation in BP through using maladaptive emotional regulation strategies (e.g., rumination, suppression). **Aims** To investigate whether people with BP have more images in a positive mood state than non-clinical controls, and whether people with BP make extreme and conflicting

appraisals of these images. To explore whether people with BP use more emotional regulation strategies in response to images. **Methods** A semi-structured interview was administered to 19 euthymic BP participants and compared to 17 non-clinical controls, requiring them to report intrusive images from a previous positive mood state, followed by questionnaires. **Results** BP participants experience significantly more intrusive images in a positive mood state than non-clinical controls, which was not explained by being a more 'imagery based' sample as there were no differences in trait use of imagery. BP participants make more extreme positive *and* negative appraisals of images than non-clinical controls. There were few differences in emotional regulation strategies between the groups, suggesting people with BP did not apply unhelpful emotional regulation strategies to these images. **Conclusions** These results further support both Holmes' (2008) hypothesis that imagery is a key internal state in BP, and Mansell et al's (2006) hypothesis that people with BP appraise the same internal state in *conflicting* ways. Future research should compare imagery to other internal states in BP to understand their relative importance.

Service Improvement Project Abstract

The aim of this study was to investigate current practice in managing suicidal ideation and prevention suicide attempts in older people's services, and to consider ways of improving practice. This is in the light of an ageing population and differential presentations of risk between older and younger adults, although there are no known guidelines in the UK to specifically manage risk in older adults. Psychologists and Community Psychiatric Nurses with at least five years experience of working with older adults in mental health services contributed to focus groups. A thematic analysis was conducted, revealing a number of factors which influence risk management in older adults; *sharing the burden*, using a *formulation driven approach*, and *clinician characteristics*. A number of *barriers* were also highlighted. The findings informed recommendations, including ways to improve team management of high risk older adults, at a time of working in ageless services.

Critical Literature Review

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What role does social identity play in post-stroke psychological adjustment?

Word Count: 7296 (excluding tables, figures and references)

June 2016

Internal Supervisor: Lorna Hogg.

Target Journal: This report is intended for submission to *Disability and Rehabilitation*, and has been written and formatted accordingly (please see Appendix A). This journal has been chosen as it is a multidisciplinary journal and focuses on the broad aspects of disability. Reports similar to this in stroke research, and similar methodologies, have been published by this journal.

1.0 Introduction

1.1 Psychological Effects of Stroke

The annual prevalence of stroke in the UK is approximately 152,000 (Stroke Association, 2016). One in 53 people in the UK live as a stroke survivor, around half of stroke survivors will live with a disability after their stroke, and over a third are dependent on others (Stroke Association, 2016). Stroke is a significant burden upon the individual, their family and friends, and wider society due to the ongoing effects of disability.

It is well documented that depression is a common difficulty after stroke, both in the acute and long-term phases (Kouwenhoven, Kirkevold, Engedal & Kim, 2011). Research continually indicates the high prevalence of anxiety and depression post-stroke (Hackett, Yapa, Parag & Anderson et al, 2005; van Mierlo, van Heugten, Post, Kort & Visser-Miely, 2015; Robinson & Spalletta, 2010). 29 percent of people will experience anxiety at five years post-stroke, 33 percent will experience depression (Lincoln et al, 2013). Psychological difficulties post-stroke are associated with longer hospital stays, affect rehabilitation and increase risk of disability and mortality (Kouwenhoven et al, 2011).

Despite the impact of depression after stroke, research continually indicates limited effect of psychological interventions, and the role of these interventions is not understood. A Cochrane review indicated no treatment effect for psychological therapy after stroke (Hackett, Anderson, House & Halteh, 2009). Individual case studies do support the use of CBT (Kneebone, 2016), however the only RCT into CBT post-stroke showed no difference in mood compared to treatment as usual (Lincoln & Flannaghan, 2003), and researchers are continually arguing for a modification of standard intervention protocols for depression after stroke (Kneebone, 2016).

Because of these limited effects, researchers have argued for a broader approach to understanding the psychological effects outside of diagnostic categories such as depression and anxiety (Crowe, Coen, Kidd, Hevey, Cooney & Harbison, 2015). Taylor, Todman and Broomfield (2011) conceptualise the wide range of psychological responses after stroke as post-stroke emotional *adjustment*, defined as having no endpoint but a fluid process within which a person makes sense of their new life after stroke, incorporating both positive and negative emotional adjustment. Taylor et al (2011) consider the difficulty in the clinical application of *adjustment* as a measurable

concept, however, and note that there are no current ways of assessing post-stroke emotional adjustment, and clinical assessment is key in this. They are, however, in the process of developing such a measure (Taylor et al, 2011). This indicates that an individualised approach to emotional adjustment following a stroke is needed.

This re-conceptualisation of psychological adjustment post-stroke has led to an increase in literature focussing on understanding the internal world of those who survive stroke and how they might make sense of and adjust to this significant event in their lives. This has resulted in focussing on mechanisms of the development and maintenance of distress after stroke.

1.2 Identity in Stroke

Taylor et al (2011) highlight the common theme of the discontinuity between pre- and post-stroke identity and sense of self within their adjustment model, indicating that beliefs about how the self has changed after experiencing a stroke are significant in adjustment. Indeed, Ellis-Hill and Horn (2000) found that stroke survivors describe themselves in more negative terms post-stroke compared to pre-stroke, and report a negative sense of self and psychological morbidity despite having both inpatient and outpatient rehabilitation. They suggest stroke survivors may settle for a restricted future due to their expectations of life with a disability.

Satink et al (2013) reviewed qualitative studies into the impact of stroke on role and the self in relation to occupational functioning, and found that developing a new self and roles was problematic and that this played a part in difficulties with self-management post-stroke.

1.3 Social Identity Theory and Stroke

The basic premise of Social Identity Theory (SIT) is that people define their *sense of self* in terms of group membership. SIT posits that part of an individual's *self-concept* originates in their knowledge of which social groups they believe themselves to belong to. This means that these social categories (eg. race, sex, sexuality, health condition, disability) provide a definition of who they are (Tajfel, 1987), dependent on the characteristics of that category (Hogg, Terry & White, 1995). Group memberships can shape our understanding of ourselves through being internalised and contributing to the development of our *sense of self*. Being a member of a particular social group can provide a positive personal identity, enhancing self-esteem and self-worth, particularly if this group is perceived to be 'superior' to others. On the other hand, if our sense of social identity is compromised in some way (e.g., we suddenly become part of a different, negatively perceived social group), this can have negative psychological consequences (Haslam et al, 2008), and develop a negative sense of self-worth (Tajfel,

1978). This is important in relation to the sudden onset of health conditions, where an individual may lose important social identities (being a healthy person), and gain a negatively perceived social identity (as an ill person). This group identity may then be internalised to a self-identity (Haslam et al, 2009).

Research indicates that life transitions can be difficult to adjust to, partly because they involve a change in group membership (Iyer, Jetten, Tsivrikos, Postmes & Haslam, 2009). Research into self-identity after a Traumatic, or Acquired Brain Injury (TBI/ABI), is increasingly using SIT to describe adjustment of identity and sense of self after such a catastrophic event (Jones, Haslam, Jetten, Williams, Morris & Saroyan, 2011; Cloute, Mitchell and Yates, 2008; Gracey et al, 2009). Research indicates that people who experience a brain injury make sense of themselves after the event in the context of their previous social roles that may have been lost (Gracey et al, 2009).

Haslam, Holme, Haslam, Iyer, Jetten and Williams (2011) found that life satisfaction post-stroke was associated with having multiple group memberships before stroke, and this was associated with wellbeing because there was a greater chance of some of these group memberships being preserved into life after stroke. Haslam et al (2011) conclude that some preservation of social identity and allowing for social identity continuity after stroke can improve wellbeing.

1.4 Current Review

The current review aims to synthesise qualitative research that includes results on identity and self after stroke using a meta-ethnographic approach, to develop a better understanding of the role of identity post-stroke and its impact on psychological adjustment. SIT will be considered as a theoretical framework within which to understand the synthesised themes.

This synthesis focussed on qualitative research as an in-depth analysis enables an exploration of empirical data which can facilitated better understand of theory. Additionally, there is a breadth of qualitative studies available in this area for review, and very few quantitative studies thus far.

2.0 Methods

A synthesis of qualitative studies that include data on identity and self-concept in stroke survivors was conducted. This included three main stages; systematic search, critical appraisal, and synthesis using meta-ethnography as described by Noblit and Hare (1988; see below for description of methodology).

2.1 Inclusion and Exclusion Criteria

Table 1: Inclusion and Exclusion Criteria

Inclusion	Exclusion
Publication in a peer-reviewed English language journal, or a foreign language journal where an English translation of the study was available	Studies did not pass the 'screening questions' on the Critical Appraisal Skills Programme (CASP; see below for description)
Qualitative Methodology	The stroke survivors results could not be distinguished either from carers, or other types of brain injury
Focus on understanding how a stroke survivor makes sense of their experience	The results did not include a consideration of identity, self-concept, sense of self, roles and/or relationships.
Included results and themes that considered identity, self-concept and sense of self. This was defined as including discussion around identity and sense of self in the theme and required a full text reading.	A qualitative synthesis of other papers
Participants were aged 18 years or older	Case Studies

2.3 Search Procedure

Potential studies to be included in the review were identified by an electronic search of three major literature databases: PsycInfo, Medline, and Scopus (see Table 2 for definitions). The following words were searched as key words, as part of the title of an article or in the abstract:

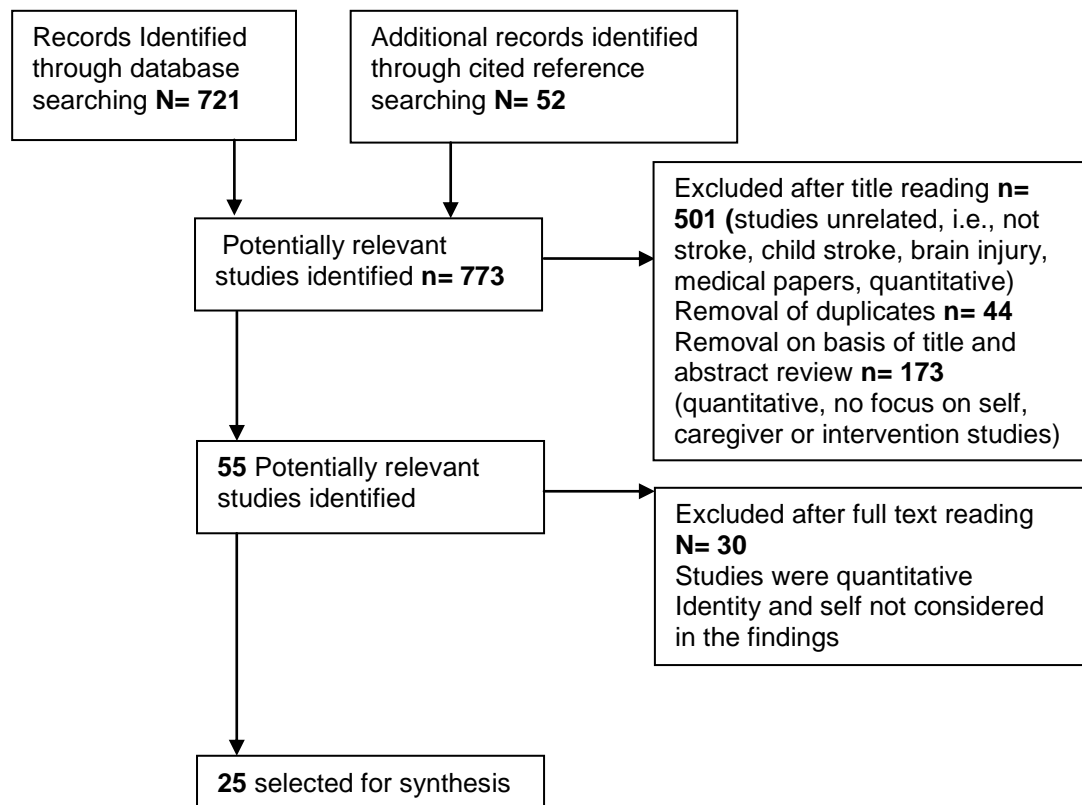
- Stroke OR "Cerebrovascular Accident" OR CVA
- Self OR Identity OR "Self-Identity" OR "Self-Concept" OR "Social Identity"
- Adjustment Or "Psychological Adjustment"

This was a deliberately wide strategy to be able to find as many relevant studies as possible. Additional references were searched for using cited references from selected studies. Please see Figure 1 to indicate how many studies were found in these searches, and how many were included. Studies were included up to the date of 5th March 2016.

Table 2: Definition of Terms

Term	Definition
'Stroke' or 'Cerebrovascular Accident'	The event of the blood supply being restricted, or stopped, to the brain (an ischaemic stroke; 85% of strokes). Less commonly, strokes are as a result from weakened blood vessels in the brain bursting (haemorrhagic stroke) (NHS choices, 2015).
Identity	This synthesis will define identity in terms of social identities and an individual's perception of their relationship with social groups. Results referring to identity , self-concept and sense of self will be considered.
Psychological Adjustment	Emotional <i>adjustment</i> , defined as having no endpoint but a fluid process within which a person makes sense of their new experience and life after stroke (Taylor et al, 2011).

Figure 1: Search Strategy and selected studies



2.4 Quality Appraisal

The Critical Appraisal Skills Programme (CASP) tool for reviewing qualitative studies was used to appraise methodological quality. The CASP includes two screening questions; is there a clear statement of aims, and is qualitative methodology appropriate. If a paper does not meet these criteria, the CASP recommends considering whether it is worth continuing with this paper. No papers were excluded

based on this criterion. The CASP then asks a number of questions related to the methodological rigour of the study (see *Box 1*).

Each paper was critically appraised using the CASP, each question scored with a 'yes' or 'no'. If it was difficult to determine this from the paper, there was a third option of 'unclear.' The CASP scores papers out of 10; the higher the score, the better quality the paper. The papers were critically appraised by RK and 20 per cent of the papers (5) were rated by two independent researchers to corroborate this process.

Box 1: Criteria used to assess the quality of the studies on the CASP

1. Was there a clear statement of the aims of the research?

2. Is a qualitative methodology appropriate?

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

4. Was the recruitment strategy appropriate to the aims of the research?

5. Was the data collected in a way that addressed the research way?

6. Has the relationship between the researcher and participants been adequately considered?

7. Have ethical issues been taken into consideration?

8. Was the data sufficiently rigorous?

9. Is there a clear statement of findings?

10. How valuable is the research?

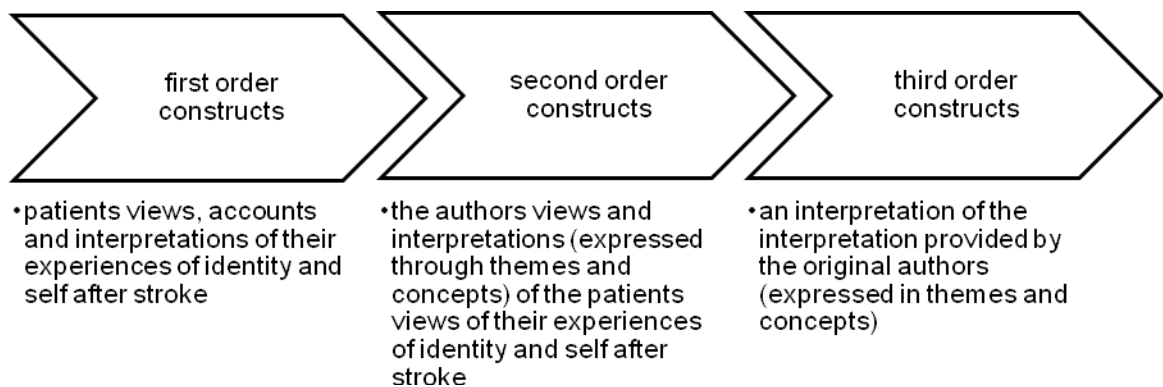
2.5 Data Extraction, analysis and synthesis methodology

Meta-ethnography (Noblit & Hare, 1988) was chosen as the method of synthesis. Meta-ethnography focuses on the "translation of qualitative studies into one another" (Noblit & Hare, 1988), aiming to develop new interpretations and conceptual insights on a body of related qualitative research findings. The aim of a qualitative synthesis is to understand and explain a phenomenon (Walsh & Downe, 2004). In this way, it reflects the qualitative methods of the studies it aims to synthesise (Britten, Campbell, Pope, Donovan, Morgan & Pill, 2002). Meta-ethnography was therefore chosen as an appropriate method of qualitative synthesis as it reaches beyond a simple aggregation and description of qualitative results (Britten et al, 2002). Instead, it seeks to understand the relationship between results and develop further theoretical understanding to better explain the phenomena under study. The product of a meta-ethnography is the translation of studies into one another.

Meta-ethnography: how the papers are related and identifying second-order constructs

Meta-ethnographies synthesise studies in a similar way to the primary data. The interpretations and explanations in the studies are treated as data and analysed accordingly; developing ‘third order constructs’ from ‘second-order’ constructs (Britten et al 2002; Malpass et al, 2009; see Figure 2).

Figure 2: definitions of first, second and third order constructs used for this analysis (drawing on Noblit & Hare, 1988 and Malpass et al, 2009).



The stages as described by Noblit and Hare (1988) were followed for the analysis of the data (see Table 3).

Table 3: Description of the seven stages of meta-ethnographic analysis

Stage	Description
Getting Started	Identifying research question
Deciding what is relevant to the initial interest	Developing search strategies for inclusion/exclusion of data to answer the question and identifying relevant data
Reading the studies	Repeated reading of accounts and noting interpretive themes and constructs
Determining how they are related	‘Putting together’ the studies. Listing key metaphors (themes), phrases, ideas, or concepts used in studies and juxtaposing them
Translating the studies into one another	Comparing the themes, concepts and interactions of the studies whilst maintaining the central themes in the original studies
Synthesising translations	Synthesising the themes and interactions in one of three ways; they may be directly comparable as reciprocal translations; they may be in opposition to one another; or together they may represent a new line of argument.
Expressing the synthesis	Producing a written synthesis as one of many possible forms.

Given the research question under study in this meta-ethnography, themes described in the original papers that related to the self, identity and roles were selected for analysis (a necessary factor for inclusion in the synthesis, as described above). Any other themes within the papers selected were not analysed. Please see Appendix B for a description of themes analysed in each of the 25 papers.

Structuring of the development of second and third order constructs in the meta-ethnography was guided by an example in healthcare research; Malpass et al (2009). The first step was to read and re-read the themes to note second-order constructs within these. These were initially read in two groups; papers that included only the stroke survivor in the data, and papers that also included caregivers. RK entered the second order constructs derived from each paper into a table, including a description using terminology within the papers and raw data from quotes from participants. The descriptions had as little re-interpretation as possible and used the original authors own words to ensure the preservation of original meaning. Alongside this, RK noted reflections that arose as the papers were read (see Appendix C).

Translating the studies into one another

The second order construct table was used as a guide for developing a third-order translation. The second-order constructs and their descriptions were read and re-read to look for repeating patterns, agreements or refutations (disagreements) within the data. At this point, it was clear that the same second-order constructs were repeating within the data available and did not differ between those studies that did and did not include caregivers. The studies were therefore analysed as one. Additionally, as the second-order constructs were re-occurring and no new second-order constructs were emerging, it was considered that saturation point had been reached within the data. The relationship between the second-order constructs within the 25 papers was developed into a third-order translation (interpretation) to understand the relationship between the studies (see Table 4).

At the end of this process, the themes were analysed to see where the HQ papers occurred within the themes. This was to understand whether the theme or sub-theme mainly occurred across HQ or LQ papers to analyse the robustness of these themes. The HQ paper references are in **bold** to mark the presence of the HQ paper, and the quality is discussed after the reporting of all the themes.

Synthesising translations

The final stage of understanding how the studies are related to one another was developed from the themes within the data; only once the original second-order

constructs were understood and developed into third-order constructs was a decision on how to synthesise the papers made. There were no situations where there were significant disagreements within the data, therefore a refutational analysis¹ was not appropriate for this meta-ethnography. Additionally, second-order constructs of one study did not wholly encompass another; therefore a reciprocal analysis was also not appropriate (Noblit & Hare, 1988). As the papers studied different aspects of identity and self (coming from different occupational or theoretical orientations or different demographics of the participants), a line of argument synthesis (Noblit & Hare, 1988) was used.

During the second-order construct analysis, two third-order constructs emerged from the data; *Relationships with Self*, and *Social Relationships*. Therefore, these third-order constructs were synthesised and described based on the data from the studies. After this, a line of argument approach was taken, as it was considered useful to add to the literature understanding the fluctuation between the relationship with the self and the impact social relationships have on this. SIT (Tajfel, 1978) was used to develop the line of argument approach, further developing the understanding of the relationship between the themes. Any contrasts to SIT were highlighted and considered in the results. An independent qualitative researcher was consulted on this process to ensure RK was adhering to the Noblit & Hare (1988) line of argument approach and ensure the description of the fluctuations between the themes was accurate.

2.6 Reflexivity of the Researcher

RK had previously worked as an Assistant Psychologist in a stroke service, and developed her interest in understanding the mechanisms of change in identity at this point. This has impacted her work in this area through wanting to search deeper into the meanings behind people's descriptions, previously finding the research in the area had not been able to accurately describe the experiences of her clients at the time. RK was new to understanding SIT at the beginning of this synthesis, so as much as is possible, looked at this with an open mind in trying to understand the phenomena under study.

¹ An analysis which involves the analysis of the refutation within the data itself, taking into account the implied relationships between the competing explanations (Noblit & Hare, 1988).

Table 4: Translation of Second-Order Constructs²

Second Order Construct	Description (Translation)	Papers
Depersonalising interactions	The stroke survivor is vulnerable to how they are treated by others and <i>positioned</i> in interactions by other people. The survivor could put themselves in one position but this could be undermined by others talking down to them in social situations. For example, others use communication strategies that alienate the person such as being talked about rather than to, and not acknowledging the person in the room. For the stroke survivors, this felt depersonalising and being treated like you are “ <i>not quite a person</i> ”. You end up discovering a new type of self through communication with others	1, 8, 10, 24
Communication difficulties	Struggling to communicate changes how the stroke survivor perceives themselves as a person and affects their identity, being unable to feel <i>normal</i> in social interactions. “ <i>Feeling like a vegetable</i> ”	11,17
Choosing to withdraw from social situations	Distancing themselves from social relationships for a number of reasons – reminds them of their former self, fear judgement of others in social situations, fearing connection with old friends because they have now changed, choosing to be self-protective because your old friends don’t understand and recognise some of the difficulties, fearing of falling short of the social norm for the age group, fear of falling short of other people’s expectations, enjoy social situations less because can’t participate in the same way because of the stroke (ability to talk, engage in conversation, follow conversation...)	10, 13, 15, 17, 19, 20, 22, 24
Friends avoid you	Some friends completely avoid the person as if reminded of their own mortality, as if a “ <i>stroke is catching</i> ”. People observed very close friends falling away and struggling to engage with the new post-stroke person and integrate the disability into the person’s social identity. This affected people’s identity and perceptions of themselves. Feel overlooked in society – “ <i>people changed their direction</i> ” – this reinforces people’s negative perceptions of themselves after stroke, undermines people’s ability to see themselves positively	1, 10, 11, 14, 17, 20, 22, 23, 24
New friends and peer relationships	New friendships were easier to make and maintain than old friendships, strangers often showed more respect than friends and acquaintances. Friendships with other stroke survivors and peers with disability was important because they had a shared world and values – these friendships were on equal terms compared to being friends with ‘healthy’ people. It felt that friendships with peers were more equal friendships in society compared to friendships with people that did not have disability, and this was helpful in maintaining sense of self compared to ‘healthy people’ friendships. One study talked about how peer friendships were difficult because it reminded them of their new disability and what it meant to be disabled, therefore did not want to interact with peers.	11, 14, 19, 22
Fear of	Fear that others would judge them negatively because of the stroke and the associated disabilities meant people did not engage	10, 13,

² Quotations from papers are in quotation marks, in italics

judgement from others	fully in social situations. Felt other people expected more of them in social situations so chose to withdraw. Role of physical disabilities and <i>feeling like a freak</i> which means people fear others will see them that way too. This affects identity through the eyes of others.	15, 17, 21
How others treat you	If people treat you like a human being (whether friends, carers, doctors, strangers...) this was important in feeling valued and still feeling like a human being, and being able to enjoy interactions with other people. Feel like they belong. If people treated them like a child, like they did not exist in interactions, or like they had no choice in situations, this would affect their sense of self negatively.	8, 10, 11, 15, 21, 24, 25
Disability stigma	Having a disability is like losing a reputation – others hold stereotyped ideas about capabilities of a person with disability and this affects their relationship with you. Also important because of how they see themselves as a disabled person – being a disabled person is being a new you and this is a negative identity to hold. It provides you with a <i>“disability outlook”</i> in social situations, colouring how you interact with the social world. The disabled state is a source of shame	1, 13, 18, 20, 21
Being dependant on others	Having to rely on other people to manage means you are not a complete person – feel like you are unable to exist as a human being on your own because you have to rely on other people. Also hold a new identity, going from being independent to a <i>“highly dependent patient”</i> , and feeling <i>“inferior”</i> in society because of this, and the struggle to accept help when needed because of what it means to have help <i>“you get very dependent and simultaneously you don’t want to be so dependent that other people take your role”</i>	6, 8, 12, 13, 14, 17, 18, 25
Loss of roles	Roles and responsibilities are threatened by the stroke event - work, finance, family and social roles. Feel like you don’t belong. This is thought of in comparison to roles previously performed in the context of previous social networks (family/work). Multiple roles are lost and felt in the sense of being less of a person. Losing your profession feels like a loss in value – not <i>“being good enough”</i> compared to before. Participants want to hold the same roles, however they are threatening because they remind of previous self. Paradoxically, if the ‘self’ doesn’t rely on physicality roles (strong/professional...) then ones value is maintained – sense of self remains intact	3, 5, 7, 8, 10, 11, 17, 22
Re-establishing roles	Finding ways of re-establishing the self through previously held roles in new ways. Role changes can also have a positive effect by finding new ways of relating to one another – <i>“the second coming of Eric”</i> , enjoying being inter-dependent in relationships and roles. Finding a way to re-establish roles <i>“blank piece of paper... well what do I want to do”</i> . Resuming life roles contributes to identity re-establishment – willing to accept capabilities have changed but still integral to self.	4, 7, 13, 19, 22
Gender roles	Gender stereotypes played a part in identity transformation after stroke- the stroke questions the very essence of being a man, for example, by not being able to provide for the family or be strong. For women – removes roles such as housewife/mother. This affects how one experiences post-stroke impairments and sense of self.	2, 8, 11, 13, 18
Total loss of self	Participants spoke of the stroke, like a thief in the night, taking core aspects of the self <i>“it feels like I don’t exist as a person, not at</i>	2, 7 – 13,

	<i>all</i> ". You become less than 100% - " <i>you are conscious enough to know that something is being taken away from you</i> ". The stroke makes you question who you are because of skill loss, lack of participation – feel like less of a person. A feeling like the old self had died, and you become a whole different person. This is because of what the stroke takes away from you (engagement, skills, activities, roles) " <i>stole a part of me – that women had died, the one that wore high heels and walked around and ran a business</i> ".	21, 25
Pre-stroke self comparison	Integral to feeling of loss of self was the comparison to previous 'self' before the stroke, which was in turn defined by roles/responsibilities/activities that a person held or engaged with – not being able to do the same things as before. The greater the gaps in doing, the greater the experiences of differences between pre- and post- stroke self – being 'good enough' in comparison to old self	3 – 6, 8, 10, 15, 16, 17, 18, 20, 21
Becoming a new person	A sense of needing a transformation into a new person as a result of the stroke " <i>cut off all my hair</i> ". Stroke can bring into focus what is important and what needs to be prioritised in one's life, allowing for an absorbing of the stroke into ones identity and turning towards a new reality	13, 15, 16, 19, 25
Self-defining activities	If activities that one defined oneself by were affected by the stroke, this changed people's views of themselves as a person. Personal identity was inextricably linked to doing things in society (" <i>being active</i> " " <i>being fit</i> " " <i>having a job</i> " " <i>being a mother</i> " " <i>being a husband</i> "...) activities and skills so interwoven into sense of self and identity	4, 8, 9, 13, 16
Finding a new way of doing	Findings new ways of being able to do previous activities helps establish continuity of sense of self between before and after stroke. Regaining skills and routines maintains sense of self.	7, 9, 10, 13
Comparison to others	Comparing oneself to others (whether that's 'healthy friends' or others who have had a stroke) can result in negative feelings about oneself resulting in a downward social comparison	17, 25
Acceptance vs. struggle of new self	Struggling and fighting against who the 'new self' is and not wanting to integrate this into ones identity, versus accepting the stroke as a new part of their life something to be integrated into sense of self.	2, 5, 11, 13, 14, 16, 19, 20, 22, 25

3.0 Results

The systematic search yielded 25 studies to be included in the syntheses.

3.1 Characteristics of included studies

Most studies were set in the United Kingdom (9/25), Scandinavia (8/25), or North America (5/25). Twenty studies had only stroke survivors as participants; five also included caregivers.

Collectively, the studies offer the perspectives of at least 334 stroke survivors and at least 53 caregivers. Although not all age ranges were reported, the studies covered a known age range of 22-86 years. Again, not all studies reported gender, however at least 162 males and 133 women took part in these studies. Rehabilitation, discharge from hospital, acute phase of recovery, long-term perspectives and aphasia were all covered by the studies.

All studies explored the post-stroke experience, with heterogeneous aims. These included understanding how family and social relationships impact participation in activities after stroke, investigating quality of life, understanding how stroke survivors experience recovery, understanding the emotional experience of stroke, exploring the meaning of confidence after stroke, understanding body changes after stroke, understanding the young stroke survivor's experience, and understanding the experience of aphasia after stroke.

The studies applied a range of methodologies, the most common being phenomenological/hermeneutic methodology (11/25) and grounded theory (6/25). Three studies did not report their method of analysis, two used content analysis, and there were single examples of ethnography (studying aphasia), interpretive design analysis and life narrative approach. Studies implemented these methodologies in a variety of ways, reflected in the differences in methodological rigour of the studies.

The characteristics of all studies are in Appendix B.

3.2 Quality

Quality ratings were made using the CASP. Rating ranged from 5 to 9.5, with a mean of 7.8. Two independent raters (one Trainee Clinical Psychologist, one Assistant Psychologist) rated 20% to ensure agreement and reliable use of the rating scale. There was good agreement. There were only slight differences of opinion, however these did not make a difference overall as to whether a paper was understood as HQ or LQ. This process indicated accurate and reliable use of the CASP.

Many studies provided little information regarding ethical issues, such as participation (Anderson et al, 2012; Boylestein et al, 2007; Erikson et al, 2010; Fallahpour et al, 2013; Kuluski et al, 2014; Kvigne et al, 2010; Murray et al, 2004; Wolfenden et al, 2012; Dowswell et al, 2000; Ellis-Hill et al, 2000; Musser et al, 2015; Pringle et al, 2013).

The majority of studies did not report on the reflexivity of the researcher in how they interacted with the data and how they examined their own role and potential bias over the data analysis, an essential process in qualitative research (Anderson et al, 2012; Boylestein et al, 2007; Burton et al, 2000; Clarke et al, 2005; Crowe et al, 2015; Erikson et al, 2010; Erikson et al, 2009; Fallahpour et al, 2013; Gallagher et al, 2011; Horne et al, 2014; Kitzmuller et al, 2012; Kvigne et al, 2000; Martinsen et al, 2012; Murray et al, 2004; Wolfenden et al, 2012; Dowswell et al, 2000; Pallesen et al, 2014; Parr, 2007; Pringle et al, 2013). This may have affected the results in that bias may not have been considered. This does not mean the reflexivity of the researcher was not considered in all of these papers; rather, it has not explicitly been reported and difficult to determine. Interestingly, in two studies the first authors had experienced a stroke, and this was discussed in relation to data analysis and bias (Ellis-Hill et al, 2000; Musser et al, 2015).

In other studies, the description of sampling methods was limited (Boylestein et al, 2007; Crowe et al, 2015; Gallagher et al, 2011; Murray et al, 2004; Thompson et al, 2009; Dowswell et al, 2000; Pallesen et al, 2014). Therefore, it is again difficult to understand whether this may have biased or affected the results in some way.

Some studies did not describe their theoretical standpoint for analysis in detail (Burton et al, 2000; Clarke et al, 2005; Kvigne et al, 2010; Wolfenden et al, 2012; Dowswell et al, 2000).

3.2.1 High Quality versus. Low Quality

HQ papers were defined as scores over 8/10, of which there were 15 papers. This was based on being above the average 7.8. Studies with lower scores, however, were included because of the value of their content, therefore the 10 LQ papers are also within the results.

HQ papers were more likely to have accurately described and have a methodologically rigorous sampling method and analysis process. Some studies categorised as HQ dropped points on the CASP on reflexivity (Anderson et al, 2012; Crowe et al, 2015; Erikson et al, 2010; Erikson et al, 2009; Fallahpour et al, 2013; Horne et al, 2014; Martinsen et al, 2012; Parr, 2000; Pringle et al, 2013).

3.3 Synthesis

The third-order translation of the second-order constructs were organised into two clear themes that occurred across the data set; *Relationships with Self* and *Social Relationships*.

3.3.1 Relationships with Self

This theme represents the way a stroke survivor develops or maintains their self-identity after having a stroke. This theme occurs in all papers across a number of sub-themes; *loss of role*; *loss of self*; *becoming a 'disabled', dependent person*; *acceptance vs. the struggle*, and *creating a new self*.

Loss of Role

Integral to an understanding of self post-stroke was the comparison to their previous roles held. This sub-theme was prevalent, occurring in 15 papers (Burton et al, 2000; Clarke et al, 2005; **Crowe et al, 2015**; **Erikson et al, 2010**; **Fallahpour et al, 2013**; Gallagher et al, 2011; **Horne et al, 2014**; **Kuluski et al, 2014**; **Martinsen et al, 2012**; Murray et al, 2004; **Taule et al, 2014**; Thompson et al, 2009; Dowswell et al, 2000; Ellis-Hill et al, 2000). The pre-stroke self was defined by the roles, responsibilities and activities the individual held before having a stroke; being an active person, a professional, a mother, a father, being a 'strong man'. If the activities that a person defined themselves by were affected by a stroke, this would change their view of themselves (Clarke et al, 2005; **Fallahpour et al, 2013**; Gallagher et al, 2011; **Kuluski et al, 2014**; Murray et al, 2004). A stroke survivor's personal identity was inextricably linked to *doing* and *being* certain things (Murray et al, 2004).

Self-identity was often defined by the social context of responsibility held towards others in relationships. An example of this would be gender roles; gender stereotypes played a part in identity transformation after stroke. A stroke can question the social construction of being a man, by not being able to provide for the family or be strong, and changes socially defined roles, such as being a housewife or a mother (Boylestein et al, 2007; **Fallahpour et al, 2013**; **Kitzmuller et al, 2013**; **Kuluski et al, 2014**; **Thompson et al, 2009**). The greater the gap between the perceived ability to fulfil these roles in the same way after a stroke, the greater the identity dis-continuity for the stroke survivor, (**Erikson et al, 2009**). This often led to a questioning of being 'good enough' compared to their 'previous self'. When a loss of role was perceived during the pre-stroke self comparison, this was experienced as being 'less of a person' (**Taule et al, 2014**).

Loss of self

Leading from a loss of role was a sense of losing the 'self' and own identity during a stroke (Boylestein et al, 2007; **Erikson** et al, 2009; **Fallahpour** et al, 2013; Gallagher et al, 2011; **Horne** et al, 2014; **Kitzmuller** et al, 2013; **Kouwenhoven** et al, 2011; **Kuluski** et al, 2014; Ellis-Hill et al, 2000; **Pringle** et al, 2013). The stroke event 'takes' something away from the person, a feeling that the 'old self' has died;

*"It's like that women had died, the one that wore high heeled shoes and walked around and ran a business and had a fantastic memory" (Participant 2, **Kuluski** et al, 2014).*

As this quote so accurately reflects, the feeling of loss was often associated with aspects of the self being taken away; skills, a lack of participation in roles and engagement in activities and social events, resulting in a feeling of not being the same 'self'. There was a common thread of being fundamentally 'changed' by the stroke and being only '*half a person*' (**Fallahpour** et al, 2013). This reflects becoming a different person as a result of the stroke. This loss of self was almost entirely defined by a loss of identity as a result of not being able to do/be/engage in the same way as before the stroke as a result of multiple losses of role. This was often linked to difficulties with psychological adjustment to the change in 'self'.

Becoming a disabled, dependent person

Stroke survivors discussed the effect of gaining a disabled, dependent label upon their self-identity and how this affected their perception of themselves (**Anderson** et al, 2012; **Erikson** et al, 2010; **Fallahpour** et al, 2013; **Kouwenhoven** et al, 2011; **Kuluski** et al, 2014; Kvigne et al, 2004; **Taule** et al, 2014; **Thompson** et al, 2009; Dowswell et al, 2000; Ellis-Hill et al, 2000; **Pringle** et al, 2013). Having a disability was described as providing the stroke survivor with a '*disability outlook*' to their life and social situations, colouring how they interact with the world (Ellis-Hill et al, 2000). Gaining a disability identity was described as a source of shame, impacting how individuals viewed themselves and their emotions negatively;

'Disability is other people and disability isn't me. I'm not disabled and I'm not going to be disabled' (participant Phoebe; Wolfenden et al, 2012)

Stroke survivors also discussed the role of depending on others to perform even basic activities and keep a routine. Identity transformation took place; from being an independent adult to a '*highly dependent patient*' (participant Eric; **Kouwenhoven** et al, 2011) and feeling like a child. This felt like being an object rather than a subject; needing to rely on others to be able to *act* in society (**Fallahpour** et al, 2013). The

effect of needing to be supported by someone else (either a carer, friend or family member) resulted in a feeling of not being a whole person having less value, compared to people that manage to live without help.

Acceptance vs. the struggle

Key to the internal world of the stroke survivor was the process of struggling to accept the differences in themselves after having a stroke (e.g., physical, cognitive or emotional), compared to finding ways to accept, acknowledge and absorb these differences into themselves and their own self-identity (Boylestein et al, 2007; **Crowe et al, 2015; Kitzmuller et al, 2013; Kuluski et al, 2014;** Kvigne et al, 2004; Murray et al, 2004; Dowswell et al, 2000; **Musser et al, 2014; Pringle et al, 2013**).

Stroke survivors struggled against the new 'disabled identity' and the loss of old identities; it felt unacceptable to have this change in identity. This, understandably, resulted in emotional difficulties in adjusting to the 'new self'.

In contrast, fewer stroke survivors spoke of integrating the stroke experience into their 'self' and acknowledging the presence of the stroke event in their life and the changes it brought. This appeared easier for the survivors who did not define themselves by activities or 'roles'. Defining the self by less active things resulted in more adjustment and psychological flexibility, and a more secure sense of self and identity (Clarke et al, 2005).

Creating a New Self

The creation of the new self was described as being able to maintain identity continuity after stroke through re-establishing roles and finding new ways of doing highly valued activities (Clarke et al, 2005; **Erikson et al, 2009;** Gallagher et al, 2011; **Horne et al, 2014; Kuluski et al, 2014; Martinsen et al, 2012;** Murray et al, 2004; Wolfenden et al, 2012; **Musser et al, 2014; Pringle et al, 2013**). This involved work from stroke survivors to adapt ways of performing 'roles' they previously held, such as finding new ways to relate to their partner and sharing household duties.

The stroke also helped redefine life priorities and the importance of different roles and relationships in life. With this process, stroke survivors would need to understand the skills important in relation to their self-identity and prioritise the losses they needed to overcome to regain their identity (Gallagher et al, 2011). This, however, was only a positive experience when stroke survivors spoke of acceptance of themselves post-stroke and the acceptance of the changes in their capabilities. Only at this point did stroke survivors move into re-establishing self in a way that incorporated the stroke into their identity;

"I sat down with a blank piece of paper and thought 'well, what do I want to do now?'" (Participant 11, Kuluski et al, 2014).

3.3.2 Social Relationships.

The theme represents the stroke survivor's interaction with the social world, and how this affects their own identities as a stroke survivor in the context of relationships with others. This theme occurred across all papers through a number of sub-themes; *friends fall away, establishing new and peer friendships, withdrawing from social situations and how others treat you.*

Friends Fall Away

A sub-theme that occurred in 10 papers was the experience of friends avoiding you after having a stroke (**Anderson** et al, 2012; **Horne** et al, 2014; **Kitzmuller** et al, 2013; Kvigne et al, 2004; **Taule** et al, 2014; Wolfenden et al, 2012; Dowswell et al, 2000; **Musser** et al, 2014; Palleson 2014; **Parr**, 2007). Survivors and caregivers talked about friends completely avoiding them as if being around them reminded them of their own mortality;

"It was very scary for them (friends) when he had the stroke. And they sort of avoided him for a while... you know, it was like it was catching or something" (participant T's wife; Musser, et al 2015).

Stroke survivors spoke of friends struggling to engage with the new post-stroke to incorporate disability into the social situation. This created a feeling of being overlooked in society, reflected in the idea that people turned away when they saw the stroke survivor again. This reinforced the stroke survivor's negative perception of themselves.

Establishing new friendships

A selection of the studies highlighted the ease of establishing new friendships, in contrast to maintaining old friendships as discussed above (**Kitzmuller** et al, 2013; Kvigne et al, 2004; Wolfenden et al, 2012; **Musser** et al, 2014). In these particular studies, this was a prominent part of the results. Participants spoke of new friends and strangers showing more respect than old friends, seeing them more for who they are.

Friendships with other stroke survivors and peers with disabilities were also important to stroke survivors because of the felt sense of a shared world and values. Friendships with other stroke survivors and peers with disabilities felt more *"equal"* compared to people without disabilities (Kvigne et al, 2010). This helped maintain a sense of self compared to 'healthy people' friendships.

In contrast to this, one paper talked about the difficulty of peer relationships because it reminded them of their new disability and what it means to be disabled, choosing to disengage with peer groups (Wolfenden et al, 2012). At the same time, there was difficulty associated with being a part of a group of people of the same age without disability because of being different, leaving the participants without a social group to be a part of (Wolfenden et al, 2012).

Withdrawing from social situations and relationships

Across a proportion of the papers stroke survivors spoke about the need to withdraw from social situations and distance themselves from relationships for a number of reasons; needing to be self-protective because friends do not treat you in the same way; fear of falling short of the social norm of the group or of other people's expectations of them; fear of connection with old friends because of the changes to the post-stroke self; enjoying social situations less because they cannot participate in the same way, and fear of judgement among others, and also "*feeling like a freak*" (Ellis-Hill et al, 2000) as a result of disabilities (**Horne** et al, 2014; **Kuluski** et al, 2014; **Martinsen** et al, 2012; **Taule** et al, 2014; Wolfenden et al, 2012; Dowswell et al, 2000; **Musser** et al, 2014; **Parr**, 2007).

Participants therefore spoke of a need to withdraw to protect themselves from these different reactions. This, however, was conflicted against missing those roles and relationships. This conflict resulted in difficulties with emotional adjustment. Ultimately, the way the stroke survivor perceived themselves in social terms, and through the eyes of others, changed the way they interacted with the social environment, impacting their self-identity.

How others treat you

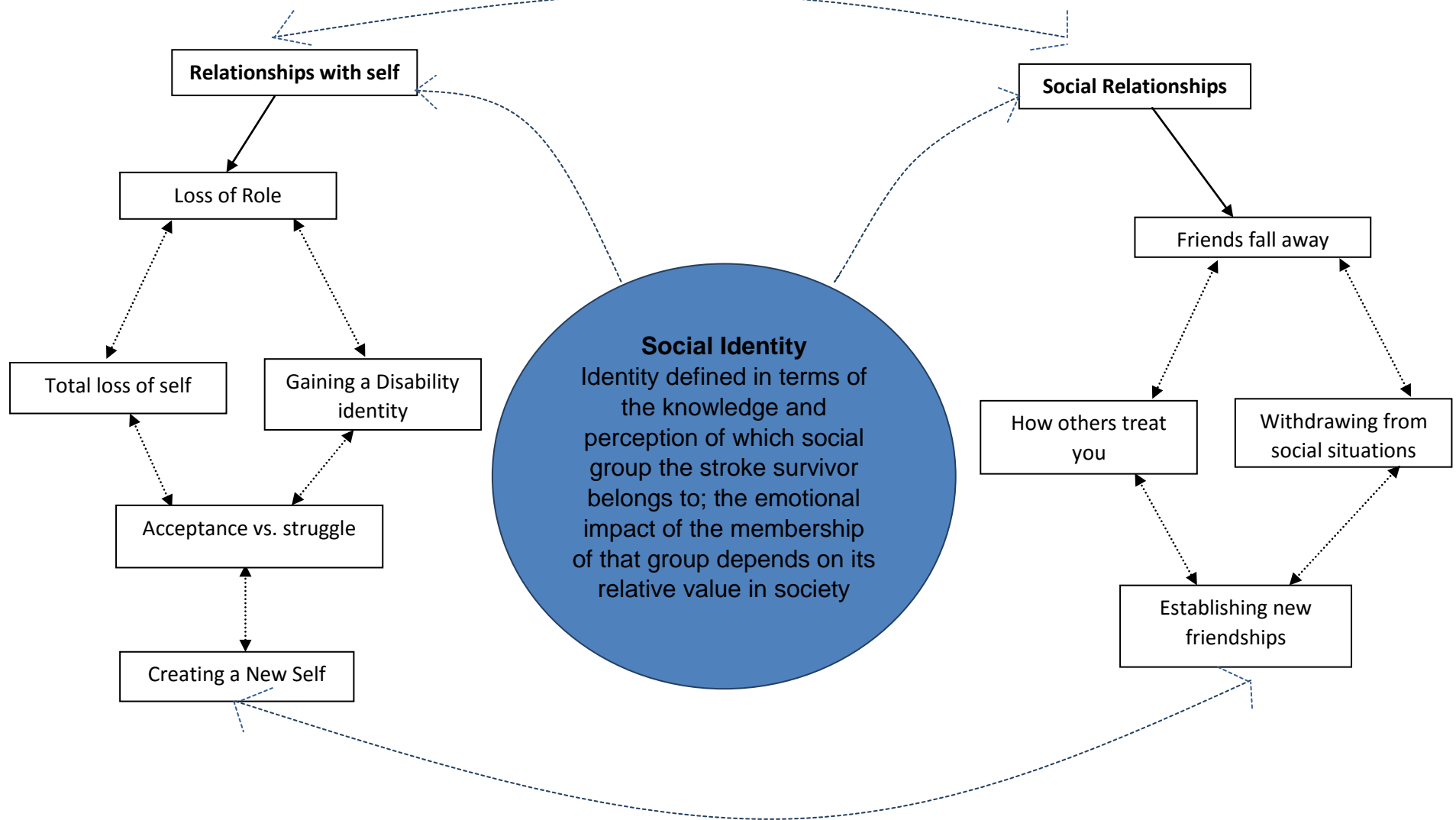
How other people treated the stroke survivor more widely within society affected how they felt about themselves as a valued member of society (**Fallahpour** et al, 2013; **Horne** et al, 2014; **Kitzmuller** et al, 2013; **Martinsen** et al, 2012; Ellis-Hill et al, 2000; **Parr** et al, 2007; **Pringle** et al, 2013). If people treated the stroke survivor like a "*human being*" (**Parr**, 2007; Kvigne et al, 2010) this was important in feeling valued, like they had something to contribute, and that they belonged. For example, even if the stroke survivor struggled to communicate, taking the time to understand and listen felt like they were a valued part of society and this contributed positively to a sense of identity despite gaining a disability.

This is in contrast to being ignored, being treated like a child, like the stroke survivor does not exist in interactions, and like the stroke survivor has no choice or valued action in situations. These situations affected sense of self negatively.

3.3.4 A 'line of argument'

Having developed the translation of the second order constructs into two broad themes, the final stage of the synthesis brings these themes together to construct a 'final line of argument'. *Figure 3* depicts the relationship between these two themes and the central concept of Social Identity at the core of this process. It shows how the stroke survivor has two parallel and inextricably linked journeys; the relationship with self and social relationships.

Figure 3: Creation of a post-stroke identity



These themes are understood as being linked through SIT (Tajfel, 1987); the reason the loss of self and identity is so important to the stroke survivor was due to loss of role, responsibility and activity in the context of relationships. The social roles previously held had been internalised to create their self-identity, therefore the process of suddenly losing them resulted in losing the sense of self, resulting in difficulties with emotional adjustment after stroke. The 'self' the stroke survivor perceives to be lost is a socially defined self as a result of internalised social identities.

In addition to this, the stroke survivor gains a 'disability identity,' a negatively perceived social role. This is reinforced by old friends and acquaintances avoiding the stroke survivor and treating them differently, as they also struggle to incorporate the change in roles and abilities into the social relationships and situations. This process results in an internalisation of the 'disability identity'. This:

- a; reinforces the stroke survivors stigma and shame associated with gaining a 'disability identity', and
- b; contributes to the stroke survivors feeling of needing to withdraw from social situations to be able to protect themselves from situations where they cannot participate in ways they used to.

The gaining of a 'disability identity' and loss of previous roles creates a feeling of distance from 'healthy people'. This can lead to a withdrawal from old social contacts and friendships, further perpetuating loss of relationships and roles. In contrast, building new friendships with others who are disabled or who have had a stroke most often creates a feeling of a shared world and 'equality' in relationships. This is understood as social creativity within SIT (Tajfel, 1978); the stroke survivor rejects the negative stereotypes of the group identity and is able to relate to other stroke survivors, and perceive them, and themselves, positively. A less common description within the data was not wanting to be associated with the 'stroke' group as it reminds them of their new disability. From a social identity perspective, this may be understood as, once having gained a social identity that they have originally perceived as a negative identity, the person may want to distance themselves and find ways of leaving the social group if possible (Tajfel, 1978). This is understood as the struggle and fight with the new identity of being a stroke survivor and being disabled; the more the stroke survivors perceive the label of 'stroke survivor' in a negative way, the more they fight and struggle with this and try to find ways of returning to 'normal'.

Acceptance of the new self and absorbing the stroke event into their identity again represents social creativity in the sense that, the stroke survivor understands the boundaries of this social group are impermeable (in that, this social group cannot be

left) and actively engages with their own sense of self to develop a positive sense of identity, which includes having survived a stroke. This results in the re-establishment of self through establishing life priorities and finding new ways of establishing important roles and relationships with others.

Establishing a new post-stroke self interacts with how other people treated the stroke survivor; whether as a 'human being', or a 'disabled person'. When treated like a human being, this enables further acceptance of the stroke as a part of their life, allowing the development of the new post-stroke self, resulting in a fluidity of emotional adjustment after stroke.

3.3.5 Quality of the sub-themes

There is no one sub-theme that has more LQ papers compared to HQ papers, whereas there are two themes with an equal amount of HQ and LQ papers (*Acceptance vs. struggle* and *New Friendships*). All other sub-themes have more HQ than LQ papers.

The sub-themes made up of the majority of HQ papers are *Becoming a disabled person*, *Friends fall away*, *Withdrawing from social situations* and *How others treat you*. This may suggest these themes are stronger, in that they are developed from the majority of methodologically rigorous qualitative papers, and therefore may reflect the post-stroke experience in a more accurate way. *The loss of self* and *Loss of Role* do occur in the majority of papers in the analysis and therefore occur across HQ and LQ papers. This, however, made it more difficult to distinguish as set sub-themes, even though this is the most commonly reported difficulty with identity after stroke.

4.0 Discussion

This meta-ethnographic synthesis of 25 studies offers a new insight into the creation of a post-stroke identity and has begun to develop a new theoretical underpinning for this. It offers a new understanding to the already established body of literature which has discussed changes to the 'self' and 'identity' in depth, without necessarily developing an understanding of the underpinnings of these changes. Synthesising this literature provides the collection of the voices of 334 stroke survivors and 53 caregivers, and developing such an in-depth perspective adds strength and provides areas for future development in understanding the role of self-identity in psychological adjustment after stroke.

This synthesis places particular emphasis on the interaction between 'self-identity', socially defined roles, and relationships with other people. In particular, it highlights how ideas about the 'self' are impacted and changed based on how others respond in

social relationships, and the shift in socially defined roles after a stroke. Many studies described the *Loss of role* and *Loss of self* as integral to identity change after stroke, resulting in distress and difficulty adjusting to life after stroke. This supports the discontinuity between pre- and post-stroke self discussed by Taylor et al (2011). This body of literature, however, has not often thought about the *reasons* why a loss of role results in a loss of self and change in identity. This synthesis adds a social identity perspective to be able to understand the underpinnings of why loss of role is so important in distress and barriers to adjusting to life post-stroke, in that previously internalised roles had resulted in the creation of self-identity, which was lost with the loss of role after stroke.

Additionally, the role of social relationships was developed in this synthesis, something which is mentioned throughout the studies yet not often focussed upon in detail. Interestingly, the quality analysis indicates the majority of these sub-themes occur mostly in HQ papers, which may mean these are ideas which emerge from data which is analysed in a methodologically rigorous way. Social relationships, and how the stroke survivor is treated within the social environment, directly impact their identity and how they perceive themselves as a person. This is corroborated by previous research, indicating the maintenance of group memberships is associated with wellbeing after stroke (Haslam et al, 2011).

Furthermore, an interesting finding to emerge from this synthesis was the strength of the *Becoming a Disabled person* sub-theme. Again, although this occurred mostly in HQ papers, it was not often focussed upon in detail. This analysis sheds light on the potential role of *suddenly* gaining a 'disability identity' plays in post-stroke identity construction when this identity is reinforced by the social environment, and then is internalised to create a negative sense of self. This can act as a barrier to psychological adjustment after stroke, in comparison to being something which creates an affinity and equality with other people with disabilities, helping to construct a positive post-stroke identity. This is corroborated by social psychology research into disability identities, which indicates both a desire to reject a disability identity because of its negative connotations and discrimination towards those who are disabled, and also a positive affirmation and pride associated with being a part of a disabled community (Dunn & Burcaw, 2013). Dunn et al (2013) highlight the paucity of research into disability identity and rehabilitation from injury, and the need for rehabilitation psychologists to focus on the effect of gaining a disability identity on an individual and their adjustment to life following gaining a disability.

4.1 Strengths and Limitations

A particular strength of this analysis is the method of synthesis undertaken. The Noblit and Hare (1988) methodology is well established within the qualitative research field, and is increasingly being recognised as an appropriate method of meta-synthesis for qualitative work. This was guided by an independent qualitative researcher and advice was sought throughout the process to be able to adhere to the methodology. Additionally, because saturation point was reached within the data, this may reflect that an appropriate amount of research was included within this study, and that further results published may reflect similar themes.

A limitation to this particular synthesis is that only one researcher (RK) undertook the actual data analysis and synthesis, which may have resulted in bias to the results process. Under the parameters of this project, it was not feasible to have a second rater for this. However, an independent qualitative researcher discussed the results and commented on the development of the themes by sorting the codes and developing the line of argument.

The meta-ethnographic approach is rigorous in its approach to synthesising qualitative research, however is it an interpretative account (Noblit & Hare, 1988). Therefore, the results discussed here may be difficult to replicate. Yet, as Noblit and Hare discuss (1988), replicability of results would not necessarily be expected, as different interpretations are encouraged, yet all should be found within the data (Noblit & Hare, 1988). The actual *method* used for the synthesis, however, is highly replicable and a strength of this approach.

There are other available qualitative synthesis methods that were considered. For example, a thematic synthesis approach can be used to compare qualitative findings, particularly in questions of effectiveness and acceptability (Barnett-Page & Thomas, 2009). However, this approach does not have a strong focus on developing a new theoretical interpretation of the data, and therefore was not considered appropriate. The 'grounded formal theory' approach (Kearney, 1988) uses the original grounded theory methodology to synthesise and generate theory from the literature available, and is perhaps more similar to the meta-ethnographic approach, aiming to reflect the methods used in primary data as a synthesis approach. This approach, however, is not specific to the process of synthesising a body of literature (rather, developed from primary data analysis approaches), and is more limited when including papers which have not used the grounded theory approach. It is also less explicit about the amount of 'interpretations' within the data, something which is important to highlight and consider when conducting further interpretation of the original data. Furthermore,

these approaches are less structured than the formal meta-ethnographic approach, which provides an explicit, rigorous, structured method to synthesise the available data. Meta-ethnography is considered as an alternative to a quantitative meta-analysis and is often considered the method of choice for synthesising qualitative research (Barnett-Page & Thomas, 2009), where the 'whole' interpretation is considered greater than the sum of its parts (Noblit & Hare, 1988). By this, the analysis aims provide innovation to the area of research, rather than a summary of current findings (Barnett-Page & Thomas, 2009).

It is interesting that the themes occurred across all of the data set given the heterogeneous aims of the studies and diverse age range, and it was considered that saturation point had been reached. Regardless of topic, participant group, or whether caregivers were involved, similar themes occurred and were evident within the narratives of stroke survivors. The content was occasionally different (roles discussed as professional vs. grandparents, for example), however, the process of loss of role and change in identity was described similarly. This may suggest these themes reflect the post-stroke identity experience across the stroke population well. A limitation of this synthesis is that few stroke survivors with cognitive impairments or severe language difficulties were included. The studies regularly exclude people who cannot communicate or have significant cognitive deficits (with the exception of one study; Parr, 2007), and therefore these findings cannot be used to understand their experience with post-stroke identity.

4.2 Quality Ratings

There is an ongoing debate about the value of quality ratings in reviews of qualitative studies (Barbour, 2000), in that it reduces the issues to a 'one size fits all' approach and may not reflect methodological rigour in qualitative research. Using the CASP to rate the studies may, in some aspects, be considered reductionist to the true form of qualitative research. The decision to include a quality rating in this analysis was made to enable some distinction between the themes in terms of methodological rigour. Interestingly, the majority of papers that were considered HQ (8+/10) employed methodologically rigorous analysis and reported this in depth, using broader understanding of the context of qualitative analysis. This may therefore reflect an appropriate use of the CASP in this circumstance.

4.3 Future Directions

This synthesis indicates the need for further exploration of the role of social relationships after a stroke. The *loss of self* and *loss of role* are well documented within the literature, yet this synthesis highlights the need to understand *why* the loss of roles

is important to an individual, and the role this plays in their psychological adjustment. Relatively speaking, the role of social relationships in identity after stroke and psychological adjustment is not well documented. This would benefit from further research into the role of social relationships in identity and psychological adjustment after stroke.

Considering clinical implications, this synthesis highlights the importance of clinicians being aware of this difficult adjustment process, providing stroke survivors with the opportunity to express this difficulty, considering novel ways to adapt to these changes. Further research is certainly needed to be able to apply this knowledge to interventions for adjustment after stroke.

4.4 Conclusions

This synthesis of 25 studies, has, for the first time, conceptualised the relationship between the 'self', social relationships, and social identity post-stroke. It considers the interactions between the relationships with the self, and relationships with other people, and how these process interplay to create a new post-stroke identity, facilitating or hindering post-stroke psychological adjustment. These findings are important in considering adjustment to life after stroke, and this needs further exploration through empirical work to apply this knowledge to interventions after stroke.

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Service Improvement Project

‘Don’t carry the load on your own....’

How staff members manage suicidal ideation and attempts in Older Adults

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Journal to be targeted: This report is intended for submission to *Archives of Suicide Research*, and has been written and formatted accordingly (see Appendix D). This journal has been chosen due to its focus on suicide, including its prevention and intervention. It publishes articles using a range of methodologies.

1.0 Introduction

1.1 Summary of relevant literature

Although reported *attempted* suicides are more common in younger people, *completed* suicide rates rise with increasing age. Males over 75 are a high risk group for completed suicide, and people over 65 are the most successful age group at completing suicide (Beeston, 2006). The attempt:completed suicide ratio in older adults is approximately 4:1, compared to an estimate between 8:1 and 15:1 in younger adults (De Leo & Scocco, 2000; Cukrowicz, Cheavens, Van Orden, Regain & Cook, 2011). With the projected estimated growth in the older adult population, the numbers of attempted and completed suicides may increase, in a generational cohort with historically high rates of suicide (Harwood & Jacoby, 2000; Conwell, Van Orden & Caine, 2011).

There are a number of specific risk factors for suicidality in older adults, in addition to common risk factors in all age groups (such as previous attempts). Particular risk factors for older adults include chronic illness, chronic pain, social isolation, loneliness, hopelessness, cognitive deficits, and loss and bereavement (Harwood & Jacoby, 2000; WHO, 2012; Walsh, 2009; Conwell et al, 2011). Older adults' acts are less impulsive, more violent, and there are often fewer occasions for rescue from their act compared to younger adults (De Leo & Scocco, 2000). Coupled with the finding that older adults are less likely to report suicidal ideation than younger adults, an older adult's risk threshold is considered to be lower than younger adults, and is more difficult to detect (Beeston, 2006).

The rise of completed suicides in older adults is conceptualised as an interaction between the ageing process and the presence of psychiatric diagnoses (Conwell and Duberstein, 2005; Conwell et al, 2011; Cukrowicz et al, 2011). Factors commonly associated with older age are suggested to interact with psychological factors, particularly hopelessness and depression (Conwell et al, 2011; Cukrowicz et al, 2011) to increase the likelihood of suicidal risk in older adults. Factors should not be considered in isolation. For example, the base rate of physical illness is so high in this population that it cannot be used accurately to predict suicide risk in older adults (Conwell et al, 2011). Therefore, suicidal risk in older adults should be understood as an interaction between social, physical, and psychological factors (Cukrowicz et al, 2011). Conwell et al (2011) suggest that knowledge of the risk factors is 'necessary but not sufficient' for risk management in older adults, and instead must be seen as a much more dynamic and developmental process which takes into account a multitude of unique factors for the individual.

Despite this complex picture of suicidality in older adults, there is a considerable lack of government attention and prevention guidelines generated for older adults in the United Kingdom. Older men are highlighted as a high risk group in the government all-age suicide prevention strategy (HM Government and the Department of Health, 2012). However, no key recommendations are suggested for older age men, compared to other high risk groups where unique suggestions are made (HM Government and the Department of Health, 2012). Crucially, they do not discuss differential presentation of risk in older adults or risk factors related to later life and the ageing process. As older adults are now the fastest growing section of the population, a lack of positive action for the prevention of older adult suicidality has the potential to have significant negative impact.

1.2 Local context

This study was based within Avon and Wiltshire Mental Health Partnership Mental Health NHS Trust (AWP). At the point of data collection, the services were undergoing transition from older adult secondary mental health services to 'ageless' community mental health teams.

A stakeholder analysis was conducted, with participation from Clinical Psychologists (CPs), and Community Psychiatric Nurses (CPNs) working within older adult teams. The AWP Suicide Prevention Lead, Dr Anthony Harrison, was also engaged from the beginning of the project to identify gaps in the knowledge of older adult suicide prevention from a wider Trust level. This did not include any service-users because the research area is in its infancy and focussed on understanding current practices within staff teams to be able to develop recommendations. Service-users could be involved for further extensions of this work.

1.3 Aims and Objectives

Considering the lack of research into implementing the knowledge of the differential presentation of risk in older adults, the over-arching aim was to consider ways to improve practice of managing suicidal ideation and prevention of attempts in older adults, and make recommendations for practice. The project had the following aims:

- Establish the knowledge-base and experience of risk management within staff members working with older adults.
- Increasing the knowledge-base of effective management of suicidal ideation and suicidal behaviours in older adults within the services.

- Make recommendations for improving practice of managing suicidality in older adults.

1.4 Specific questions to be addressed

1. Do staff feel knowledgeable, experienced and confident at managing suicidality in older adults?
2. What are the approaches taken in managing suicidality in older adults?
3. What do staff members think could aid the management of suicidality in older adults?

2.0 Methods

2.1 Participants

Purposive and snowball sampling was employed to recruit 11 participants (9 female), five CPNs and six CPs through contacts with the service. All staff members had at least five years clinical experience of, and were currently working with older adults with mental health difficulties. As the questions focussed on understanding clinical practice, those with less than five years experiences were excluded, enabling participants to have experience to draw upon, whilst also practically being able to recruit enough participants locally.

During the stakeholder analysis it was considered appropriate to include CPNs and CPs because of the likelihood of their day-to-day work to involve managing suicidal risk in their older adult clients, and practically due to the availability of participants who worked in the service.

2.2 Procedure

Prior to recruitment and data collection, full ethical approval was gained from the University of Bath's research ethics committee. AWP Research and Development indicated that NHS ethics was not required.

Participants were approached via the project's external supervisors' professional contacts and invited to take part in the study. In total seven CPNs were invited to take part; two were excluded because they did not have five years experience. Six CPs were invited and all were included.

A focus group methodology was chosen for data collection as it relieved pressure on individual participants in contributing throughout, and allowed participants to be able to develop each others' ideas. The stakeholder analysis agreed this was a beneficial

methodology to enable participants to generate ideas, a recognised strength of a focus group methodology (see Kitzinger, 1995). Focus groups with one type of professional (CPs or CPNs) were chosen in comparison to mixed-professional groups due to the possibility of power imbalances with professions.

Two separate focus groups (CPs and CPNs) were conducted. These were guided by a semi-structured interview schedule based on the research aims (see Appendix E), which was used to guide discussion.

2.3 Methodological rationale

Due to the novelty of this area, and the focus on exploring people's experiences and knowledge, the qualitative approach of thematic analysis was chosen to allow for a rich exploration of their experiences, a recognised strength of this approach over a quantitative approach (Braun & Clarke, 2006). It reflected the nature of the research questions; it is not tied to a particular theoretical framework, and would allow for the development of patterns of meaning around the aims of the research (Braun & Clarke, 2006).

3.0 Data Analysis

3.1 The Researcher's Perspective

The investigator (RK) has worked in older adult services (mental health, physical health and memory clinic services). During these work experiences, RK has worked with clients expressing suicidal thoughts. This experience may have resulted in some bias in the understanding of risk management in older adult services, in that RK may have held some beliefs about best management approaches. RK, as much as possible, held an open-mind during analysis. This bias was also managed as much as possible by using an external second-rater in the analysis approach.

3.2 Epistemology

A number of decisions were taken to be able to analyse this data, using the Braun and Clarke (2006) approach to thematic analysis as a guide. These decisions were guided by the research aims and questions and were as follows; the data was analysed from an essentialist/realist perspective, using an inductive approach, because the project was not aiming to fit within an existing theoretical framework. The codes and themes were developed from a semantic level, looking at explicit meanings within the data.

3.3 Data Analysis Approach

The focus groups were audio recorded, transcribed verbatim by RK, and checked against the tape recordings for accuracy. They were analysed using the Braun and Clarke (2006) method of thematic analysis.

Once transcribed, RK read the two focus groups through three times to identify codes manually within the data. Codes were any piece of information within the data which was interesting in relation to the research questions. Once codes were collated, they were sorted into initial potential themes, looking at patterns within the codes and data extracts. These were reviewed and refined through looking at connections between the themes, and re-reading the data to establish whether the themes developed fit with the data.

The data sets were also coded by a researcher external to the project. The themes were discussed and cross-referenced. At this point, the themes were further refined and finalised. Overall agreement between the researchers was good, in that the themes developed by both reflected similar constructs. A thematic map was developed at this point (see Appendix F).

A summary of the findings was sent to five participants to determine whether the analysis and interpretation matched their understanding of the topic and accurately reflected their experience. Two responded, one CPN and one CP. They both supported the analysis and felt it fit with their experience.

4.0 Results

Four main themes were identified from the analysis: *Sharing the Burden*, *Formulation Driven Approach*, *Clinician Characteristics* and *Barriers*. A number of sub-themes were developed within these (see Table 1).

Table 1: super-ordinate and sub-ordinate themes.

Super-Ordinate Theme	Sub-Ordinate Themes
Sharing the Burden	Client Clinician and Team
Formulation Driven Approach	
Clinician Characteristics	Previous Experiences Confidence and Intuition
Barriers	Social Isolation Blanket Approach Pressure on Time Culture of Blame Risk Procedures

The relevant themes are described below and discussed alongside anonymised quotes from participants.

4.1 Sharing the Burden

This was a key concept apparent within both focus groups. It was described for both the *client* being able to share their painful thoughts and feelings, and for the *clinician* being able to share this within the team.

4.1.1 Client

Participants described that their client is able to share the unbearable nature of their feelings more easily when a strong therapeutic relationship is developed and well established with their clinician. Being able to express their unbearable feelings with the clinician made it easier for a clinician to manage their suicidal thoughts than when older adults could not share these. In the case of attempted suicide, it was often expressed by the participants that the clients were communicating their unbearable pain that they had been unable to share verbally. This therapeutic relationship is built on having time available for the client and key skills of listening:

CP 6: “so much of this comes down to the relationship you build with a person and that sense of developing a relationship in which people are able to share these difficult ideas about what they want to do to themselves” (participant 6)

CPN 2: “the most important thing we do is listen” (participant 8)

4.1.2 Clinician and Team

Participants described that as a clinician, you become able to bear the unbearable feelings of clients when you have a team to share the weight of this work, and decision-making around risk. Being able to work with the team around you, discussing cases and sharing the burden of holding risk was discussed as enabling them to work with the

suicidal older adult client in a more effective way. Conversely, not being able to share with the team creates difficulties in managing these clients;

CP 3: “the tolerance for positive risk taking, perhaps, is greater the more it is shared and the sense that you have reasonably talked about it” (participant 3)

CPN 4: “I co-work with the psychologist (on a case) so that feels really beneficial that there’s two of us... the ability to go back to the office and talk it over” (participant 10)

CP 4: “don’t carry the load... (on your own)... because then what can happen is that person goes into risky mode and somebody is admitted, possibly unnecessarily” (participant 4)

To share this burden, allowing time for space and reflection together to enhance learning was important in allowing an individual clinician to hold the burden and risk of a client.

CP 4: “adding reflective space, the value of that... what can we learn from this and that sense of something being held communally and something coming out of that that you might not be able to predict by way of ideas” (participant 4)

There was a feeling within the participants that the need to share the burden of this work within the team was similar to the effect of the client being able to share their burden;

CP 6: “I think there’s a parallel between what we’re saying we want to provide for our client that we want to provide a space in which they can ... share things that are really hard, and we need to be able to do that similarly with our colleagues and team” (participant 6)

4.2 Formulation Driven Approach

Throughout the two focus groups, participants were clear that taking a ‘one-size-fits-all’ approach to managing risk in this client group is ineffective and does not fit their clinical experiences. It was continually discussed that developing a formulation (a shared understanding) and considering the situation-person interaction was essential;

CP 3: “there are those overarching things such as being male... the statistics, I suppose, what always makes me think about the importance of formulation because those factors may or may not be relevant with the particular person you’re working with... having a sense of that is kind of helpful, just to think about things more broadly” (participant 3)

This was in contrast to using standard information about 'protective factors'. Participants were clear that what looks like on the face of it as a 'protective factor' can mean different things for different clients, and the meaning behind the factor must be explored to understand and manage their risk. This was accompanied by recognising the unique nature of suicidal risk in older adults, in that the unpredictability of risk in older adult clients and the subtlety of their thoughts and acts results in a fragile and unique presentation needing an individual approach. For example, their risk can be very dependent on weak 'protective' factors that are unique to the individual;

CPN 4: "(a) very changeable position that's difficult to keep on top of"

(participant 10)

CP 5: "there's something for me about checking out protective factors... for some older people I see I think they have quite weak protective factors and sometimes it can come down to "oh well the budgie goes" and that's it"

(participant 5)

4.3 Clinician Characteristics

This describes the individual differences of the clinician. Participants continually spoke about the nature of their own *previous experiences* in working with older adults, and their *confidence and intuition* in being able to work with their current clients who might be expressing suicidal thoughts.

4.3.1 Previous Experiences

Participants spoke of the profound experience of clients who had completed suicide, and this affecting their current risk management through being more aware and accepting of the challenging nature of this work;

CP 6: "this work potentially involves somebody losing their life, it stays with you but I think it is something you can find useful. The experience I had of somebody who did kill themselves, I will never forget him and any of that circumstance around that piece of work, but I think I can use that in a way that feels helpful for other people" (participant 6)

4.3.2 Confidence and Intuition

Participants spoke about how the nature of their experiences has shaped their confidence in managing risk. It could have negative effects particularly if the clinician was not well supported during this experience, and could have positive effect in that it could affect future approach to risk management. There was a sense it is something

which develops over time and increases clinician 'instinct' or intuition in dealing with unexpected risk with clients.

CPN 2: "if there's something instinctively we pick up or some sense of 'I don't want to leave this person for some reason but I don't know why', so sometimes it can be less about using cognition and logic and sometimes a bit more about emotion" (participant 8)

Working together as a team to build confidence in risk management and enable a discussion about the difficulties in working with risk in this client group was considered important;

CP 2: "what I'm going to suggest is that we as a team actually do things on confidence in dealing with suicidality, what are we not talking about that, when people are saying 'I can't cope with this, I don't have experience in this'. It's interesting that it is a topic that hasn't been touched... so that's something I'm going to go and do because of this discussion today" (participant 2)

4.4 Barriers

Barriers to effective working in managing risk in older adults were discussed throughout. These restricted a clinician's ability to maintain effective therapeutic relationships and share the burden within the team, and affected the individual clinician's confidence in their ability to manage risk.

4.4.1 Social Isolation

Participants discussed this continually throughout both focus groups. It was described as something which maintains a client's suicidal ideation, their loneliness and hopelessness. Participants spoke clearly of having nowhere for their clients to go once they had got through the difficult times, which means that eventually the situation will repeat itself and the client will become risky again. Participants continually suggested that the lack of support available within a community means the service becomes the clients' social network, holding clients who remain in a hopeless position because of their social situation.

CPN 3: "that's the hardest when you're visiting people that haven't got that support around them and you suddenly take on the whole ownership of the situation" (participant 9)

CP 2: “Just looking at how we cope clinically is missing part of the picture I think... looking at broader issues as to why that’s happening... economic problems, isolation” (participant 2)

4.4.2 Blanket Approach

The CPs in particular spoke about the ‘risk averse’ nature of the Trust could sometimes be restrictive in managing older adult risk. This was particularly in reference to a ‘one-size-fits-all’ approach to risk events within the Trust, which did not fit the clinical work of older adults and could actually be restrictive to their recovery;

CP 2: “through the 9 years of being there no-one in the older adult ward needed that³ [environmental change on the ward] and it made their recovery process harder” (participant 2)

4.4.3 Pressure on Time

Participants were clear that pressure on time was a prominent factor in their ability and time available to manage risk. The current pressure to manage cases quickly and reduce caseloads puts direct pressure on a clinician’s ability to provide time and space to develop a therapeutic relationship to allow clients to share difficult feelings. This is in the context of change within a Trust level, creating a struggle for individual clinicians between being able to develop relationships with clients and manage their risk.

CPN 4: “so I think that’s a worry from now and for the future, if there’s more pressure on us to move people on quickly, give a short sharp input and go, then these things will happen more and more” (participant 10)

4.4.4 Culture of Blame

An important factor within the CPs in particular was the blame felt when previous attempts or completed suicides by their clients had occurred. Participants spoke about the Root Cause Analysis (RCA) process, in that even though RCAs are there to reduce blame upon individuals, clinicians still feel a component of blame, and individually can blame themselves. This was discussed as having a direct impact on being able to develop their own confidence in managing risk.

³ This refers to an environmental change in all of the inpatient wards in the Trust which resulted in all the doors being removed because of the risk of hanging. The participants expressed that this impacted greatly on older adult clients, who did not display risk of hanging in the same way as working age adults.

CP 5: “having an opportunity in a non-blaming way, which is different from an RCA, being able to as a team come together and have a debrief which is facilitated by someone outside would be really helpful” (participant 5)

CP 1: “I think there’s something about culture ... that isn’t always someone’s fault” (participant 1)

4.4.5 Risk Procedures

Participants commented that risk checklists available for use within the Trust do not match the participants’ experiences of managing risk in older adults. Participants spoke about how checklists are actually an anxiety management technique for the Trust and clinician, and ineffective in actually managing risk clinically. This is in the context of using a formulation driven approach, and being able to hold that in mind whilst also using a checklist;

CP 2: “I was thinking about the checklist of suicidality and how that might give us a sense of comfort, we’ve done that checklist and we know where they are, and actually you don’t really know, and it can be the people that you don’t think are high risk, so that sense of keeping an open mind really” (participant 2)

5.0 Service Feedback and Recommendations

Recommendations for good practice of managing suicidal ideation and preventing attempts with older adults are included in Appendix G.

The following areas of need for development were identified from the above results; clinician peer support; older adult specific risk management approaches; focussing on the therapeutic relationship with older adult clients; working with a socially isolated group, and perceived blame. A number of recommendations have been made in these areas of need.

The results and recommendations have been discussed with colleagues who have taken part in the project. Feedback focussed on formulation driven approaches, and utilising complex case formulations within their teams for complex, at risk clients. They felt this was a valuable contribution to their services, and would address concerns such as communication within teams, team working, and finding support for resource-intensive clients. In terms of future evaluations of these recommendations, it would be important to re-assess clinicians risk management approaches and evaluate whether complex case formulations around clients who are high risk has helped individual clinicians, and the wider teams in managing risk. This was outside of the scope of this

project, however future service improvement projects may be beneficial in analysing this. Please see Table 2 for further description of recommendations.

The results and recommendations have also been fed-back to Anthony Harrison, Suicide Prevention Lead for AWP. This discussion focussed on service level issues, such as providing emphasis for the unique nature of older adult risk in a time of ageless services, and the need to manage perceived blames in root cause analysis processes. Anthony intended to take this forward to the suicide prevention board within AWP.

Table 2: Recommendations

Recommendation 1	
Area of need	Peer Support
Issues raised	In the current context of change, participants felt time and space for peer support and reflection was neglected and not seen as necessary within the teams. Participants did feel this work was integral to their ability to work as older adult clinicians, and therefore felt time for peer support for older adult staff should be valued in the context of change to ageless services.
Recommendations	<p>Peer support is provided outside of team meeting space, with the aim of reflecting on the difficult nature of this work and discussions about sharing knowledge and improving confidence in working.</p> <p>Another focus of peer support could be to understand the role of developing therapeutic relationships with older adults, and how to develop skills in this to support effective risk management. This might involve staff learning sessions outside team meetings, where staff could share knowledge about developing effective therapeutic relationships and build on recent evidence-based practice.</p> <p>Co-work on resource-intensive clients with high risk to support staff. For example, if a staff member is finding one client takes up a large amount of their time and is finding this work difficult, co-working on this type of case has been found by our participants to reduce burden and increase effectiveness of working.</p>
Recommendation 2	
Area of need	Older Adult specific risk management approaches
Issues raised	Participants found taking a blanket approach to risk management difficult and restrictive for older adult client's recovery, and felt that because services have changed to

	ageless, the specificity of older adult risk management is not being developed within the trust.
Recommendations	<p>The provision of complex case formulations where working with resource-intensive, high risk clients. This should be provided outside of team meeting space, and may be facilitated by psychologists from within the team. Additionally, a psychologist from outside the team could also facilitate such a meeting to enable a more objective look at the case.</p> <p>Consultation with older adult clinicians about developing older adult specific risk information for the trust. This could be a specific piece of work which develops an 'older adult risk profile', paying attention to the differences between older adults and younger adults to be used within risk management approaches in older adult working. This could potentially be completed by a trainee clinical psychologist whilst on an older adult placement.</p> <p>Consultation process on older adult inpatient wards on risk management approaches to specify the difficulties in 'one-size-fits-all approach'</p> <p>A continuing focus on formulation-driven approaches, understanding the changing nature of protective factors in particular. This may include keeping 'risk management' on a team meeting agenda, focussing on formulation driven practice.</p>
Recommendation 3	
Area of need	Focus on therapeutic relationship with older adult clients
Issues raised	Participants felt with time pressures within the trust, they are being asked to build these relationships in short time frames which are very difficult with this client group.
Recommendations	<p>Therapeutic alliance is monitored in therapy where clients are at high risk, through supervision. This may be achieved through a rating scale of therapeutic alliance, for example. A supervisor could also keep this item on the agenda, allowing for personal reflection within the individual clinician about the therapeutic alliance.</p> <p>The need for therapeutic relationship is reflected in care pathways – reduce the amount of clinicians needed at transition points, in particular. This point was raised with Dr Anthony Harrison and he was considering how to take this recommendation forward. For example, this may involve being aware of the difficulties with transition for older adult clients and increasing availability for contact at that point with a key worker.</p> <p>As a team, have an awareness of high risk clients who need more time and resources for clinical work. This may involve having a repeating item on the team meeting agenda for 'higher-risk' or resource-intensive clients, and allowing for repeated opportunities for these clinician's to seek support around these</p>

	clients. This is particularly important as team's transition into more 'mobile working'.
Recommendation 4	
Area of need	Working with a socially isolated client group
Issues raised	A continued difficulty for the participants is working with a client group who are socially isolated, with a sense that this social isolation can maintain a client's hopelessness and increase their suicidal thinking.
Recommendations	<p>Within the ageless teams, need to be mindful of the older adult specific voluntary sector. Ageless teams need to be able to understand the specific voluntary organisations available for their older adult clients, and share this knowledge within the teams. It may be that older adult clinician's take a lead of this within the teams.</p> <p>A review into the links with voluntary sector for older adult clients, and how to improve key services within the area, with clear communication and referral links. This may be an appropriate consultation project for a trainee clinical psychologist.</p>
Recommendation 5	
Area of need	Perceived blame
Issues raised	Participants felt that even though the RCA process is non-blaming, blame can still be felt individually
Recommendations	<p>Staff continue to be supported within supervision when going through an RCA. The issue of feeling blame should be recognised and discussed in supervision and its potential impact on future work. This may involve support from within the team (i.e., their supervisor, or independent senior member of the team), or the staff member could also be made aware of support from the wider trust from occupational health.</p> <p>Debriefs and support for a team when a serious incident has occurred and the team are going through an RCA.</p>

6.0 Discussion

To date, the majority of research into older adult suicidal ideation and attempted/completed suicide has focussed solely on the presentation of older adult suicidality. This research body, at the time of writing, has not accurately been translated into improving practice of managing suicidal ideation and attempts in older adults in the United Kingdom. This is despite the knowledge that older adults can and do present differently in this manner compared to working age adults.

The developed themes highlight a number of issues in relation to improving practice in managing suicidal ideation and attempts in older adults. In reference to the original aims of the research, the participants felt their confidence and previous experiences were important factors in managing risk, and did not comment on feeling knowledgeable. Confidence was discussed by both focus groups, and was thought to be a key factor in the participants' ability to perceive risk. Confidence could be affected by previous experience in clients attempting and/or completing suicide. It could be enhanced through the support of their team; the more cohesive team decision-making was around risk, the easier it was for participants to feel supported and confident in their decisions.

In reference to the aim of understanding what approaches are taken in managing suicidality in older adults, team decision-making and peer support were key for the participants in managing complex risk situations. Other key approaches included maintaining a strong therapeutic relationship with the client to enable them to share difficult feelings; to be able to share this burden with the team; and to take a formulation driven, individual and unique approach to understanding risk in their clients. The participants' felt from their practice that the more this multi-faceted approach is used to manage risk in older adults, the better the risk management within individual clinicians and teams it becomes.

The need for a strong therapeutic relationship is supported by previous research, which indicates that older adults are less likely to report suicidal ideation (Harwood & Jacoby, 2000). The effectiveness of a formulation driven, unique approach to managing risk in older adults is reflected in their risk profile being more subtle and difficult to detect compared to working age adults (De Leo & Scocco, 2000; Beeston, 2006), and reflects the complexity of the interaction between the ageing process and psychiatric difficulties in suicidality in older adults (Conwell et al, 2011; Cukrowicz et al, 2011). This is supported by Conwell et al's (2011) discussion about knowledge of risk and protective factors being necessary but not sufficient in risk management of older adults; it is argued that taking account of their complexity is also essential and is not accurately captured in statistics.

In reference to what participants' felt could aid the management of suicidality in older adults, participants mainly discussed the barriers they were coming across in their day-to-day practice that restricted effective management. A number of barriers restrict the participants' ability to effectively manage risk, and restrict the development of risk management approaches in older adult services. These barriers make it more difficult for clinicians to develop team working (*pressure on time, a culture of blame*), to

develop confidence in managing suicidality in older adults despite the use of risk checklists (*a culture of blame, risk procedures*), to develop strong therapeutic relationships (*a pressure on time*), and to effectively manage maintaining factors to a client's hopelessness (*social isolation*).

Social Isolation was a strong factor within the data-set, with a sense of hopelessness and powerlessness of the clinician's struggle to change this nature of the client's situation. Regardless of the client's mental health, clinicians felt the weight of the individual's social isolation in their maintenance of risk in older adults. This supports the growing research area into interpersonal aspects of suicidality, including perceived burdensomeness (Cukrowicz et al, 2011).

6.1 Limitations

It is possible that this sense of hopelessness within the participants hindered the development of ideas for effective management, and biased the results to discuss more negative aspects of their work. Therefore, it was more difficult to answer the question of what participants felt could aid management of suicidality in older adults, and may have limited the development of the results into recommendations for improving practice.

Whilst the focus group methodology has strengths, it also has some weaknesses. It is possible some participants did not contribute some ideas due to fears of judgement from their work colleagues and may not have been as honest as they could have been in an individual interview. Additionally, two sub-themes within the *Barriers* theme (*Culture of Blame* and *Risk Procedures*) were mostly unique to the CPs focus group. This may reflect different roles and responsibilities between CPs and CPNs, and the different experiences of individuals within the groups. For example, the CPs role of understanding complex formulations may reflect why *Risk Procedures* felt restrictive to them rather than helpful, as the procedures may clash with their role of formulation. The *Formulation Driven* theme was not unique to CPs, however the more complex nature of formulation was reflected in quotes from the CPs rather than CPNs. The aim, however, was not to analyse the professions separately, and instead integrate the results to be able to develop recommendations for the whole team to understand and be able to use.

Another possible limitation is the decision to have separate profession focus groups. Whilst this has benefits in limiting issues with power imbalances between the professions, a joint professional focus group could have potentially resulted in different data, resulting in different results. For example, it is possible that the hopelessness

within participants would have been expressed differently within a mixed group, potentially with differing opinions, resulting in richer discussion around this. Furthermore, the complementary nature of the CPN/CP professional relationship may have resulted in a more balanced discussion around risk management, rather than some results being more weighted towards the CP focus group (*culture of blame* and *risk procedures*). It is, however, important to note that, with the exception of these two sub-themes, all other themes occurred across the focus group, which may indicate similar results would have occurred with mixed groups.

Additionally, there are a slightly higher proportion of CP quotes to CPN quotes used to develop the themes. This may be due to the amount of pressure the CPNs were under at that time in their work, which may have contributed to their feelings of hopelessness. This may have resulted in their focus group being unable to reflect as much as the CPs in relation to the original aims of the research. Finally, the researcher is a CP in training, which is likely to have biased the quotes used because the researcher may think in similar ways to the CP participants. This could have been counter-balanced by asking a researcher from another profession to analyse the results. This, however, was not feasible within the parameters of this project.

6.2 Future directions

Further research is needed into the management of suicidal ideation and suicide attempts in older adults. In particular, comparisons should be made into risk management practices with older adult clients compared to working age adults, to determine whether the current approach in older adults is the most effective in matching the clinical need of this population. Additionally, an evaluation of the recommendations and improvements within this current service would be appropriate to determine the usefulness of tailoring the risk management approach in older adult services.

6.3 Conclusions

These results indicate the importance of team working, developing cohesive team relationships, enabling strong therapeutic relationships and developing a unique, formulation driven approach to risk management in older adults. Additionally, the results point to the role of confidence within individual clinicians and how this can be developed within teams, and a number of barriers that restrict risk management practices within these older adult services. Recommendations for effective risk management in older adult services have been developed in response to these results.

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Main Research Project

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Investigating intrusive imagery, appraisals and positive mood states in Bipolar Disorder

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Internal Supervisor: Dr James Gregory, Clinical Psychologist

External Supervisor: Dr Warren Mansell, Clinical Psychologist

Target Journal: This report is intended for submission to *Behaviour Research and Therapy*, and has been written and formatted accordingly (please see Appendix I). This journal has been chosen due to its focus on understanding emotional and behavioural disorders. They encourage papers that investigate mechanisms that contribute to psychopathology. Reports similar to this in bipolar research, and similar methodologies, have been published by this journal.

1.0 Literature Review

Historically, Bipolar Disorder (BP) has been understood within a medical model, reflected in the fact that primary long-term treatment is pharmacological (NICE, 2014). In recent years, the evidence-base for psychological understandings of BP, and psychosocial interventions has grown, with mixed outcomes (Geddes & Miklowitz, 2013), with increasing suggestions for psychological interventions (NICE, 2014). Cognitive Behavioural Therapy (CBT) has been found to reduce relapse rates and shorten the length of episodes of depression, however the significance was modest and there was little evidence for long-term benefits (see Richardson, 2010, for a review). A recent meta-analysis (Oud et al, 2016) indicates that some, but not all, psychological interventions reduced relapse rates and hospital admissions. Some improved depressive symptoms, however they found little impact on mania symptoms or quality of life, and no data was available on which interventions may help those with more severe BP (Oud et al, 2016). Further research is needed into the understanding of the psychological processes in BP, particularly within mania because the above research indicated little effects in intervention (Oud et al, 2016) and continuing to add to the understanding of this could lead to focussed psychological interventions (Geddes et al, 2013).

Psychological Theories of BP

There are a number of relevant psychological theories indicating the mechanisms behind BP. An influential theory indicates that mania is related to an elevated sensitivity to reward with a more reactive Behavioural Activation System (Johnson, 2005). Life events related to reward and increases in goal pursuit can predict increases in manic symptoms (Johnson, 2005), suggesting rewards and goal pursuit may help explain the development of mania (Johnson & Jones, 2001). Furthermore, the beliefs people with BP may hold about different mood states and the way these are appraised have been hypothesised to play a role in the development of mania (Jones, 2001), with the majority of research focussing on overly positive appraisals of the self or mood. Indeed, risk for mania has been found to be related to overly positive interpretation of manic symptoms and being overly confident in response to success (Johnson & Jones, 2009).

Other theory and research indicates the role of negative, as well as positive appraisals as having a role in mood variation in BP (Mansell, Morrison, Lowens & Tai, 2007; Kelly, Mansell, Sadhnani & Wood, 2012). This is supported by research which indicates

people with BP actually try to avoid rewarding activity as a means of preventing mania, and try to dampen positive affect, which subsequently lowered quality of life (Edge et al, 2013). This suggests that mania and positive moods in themselves are conflicting and present both positive and negative beliefs and appraisals to the individual.

Evidence is also growing indicating the role of imagery in goal pursuit, in that mental imagery can promote goal-directed behaviours and in fact improve goal attainment (Chan & Cameron, 2012). Evidence is growing in implicating the role of imagery in mood escalation and de-escalation in BP (Holmes, 2008), and coupled with difficulties in goal pursuit this indicates imagery in itself is important to investigate within mood states in BP. This study, therefore, will focus on investigating the relative role of positive and negative appraisals, and imagery in BP.

Extreme Appraisals

An influential development to the theoretical understanding of BP is the cognitive model of mood swings (Mansell, Morrison, Reid, Lowens & Tai, 2007). It is proposed that intrusions into awareness, such as emotional, cognitive or physiological changes in internal states, are appraised as having *extreme personal meaning*, which are *multiple* and *conflicting*. These internal state changes may mean imminent catastrophe, personal success or weakness, and may trigger behaviour to attempt to control this imminent success or failure resulting in escalation or de-escalation of mood (Mansell et al, 2007).

Mansell and Jones (2006) confirmed the presence of these extreme, conflicting appraisals in BP participants compared to non-clinical controls, after controlling for symptoms of BP, using the Brief Hypomanic Attitudes and Positive Predictions Inventory (HAPPI; Mansell et al, 2006). Additionally, Dodd, Mansell, Morrison and Tai (2011) found that after controlling for baseline BP symptoms, extreme appraisals were independently associated with symptoms of activation, depression and conflict one month later (Dodd et al, 2011). This suggests that extreme and conflicting appraisals have a relationship with BP symptoms, however the causality of this is unknown.

The importance of making both *positive* and *negative* conflicting appraisals of internal states has also been indicated. Those with BP appraised activated states with both positive and negative appraisals, compared to unipolar depression (Kelly, Mansell, Wood, Alatiq, Dodd & Searson, 2011). This suggests that the presence of conflicting positive and negative appraisals is a unique feature of BP. In a non-clinical sample, Kelly, Mansell, Sadhnani and Wood (2012) found the same internal states could be appraised in extreme positive *and* extreme negative ways and these had a strong relationship with hypomania and depressive symptoms respectively. Those who

appraised activated internal states in extreme positive ways experienced hypomanic symptoms, those who appraised the *same* state in extreme negative ways experienced depressive symptoms. Kelly et al (2012) hypothesised that those who appraise internal states in either extreme positive or negative ways strive to use emotional regulation strategies (e.g., through cognitive control strategies, such as rumination and suppression) to modify this appraisal, resulting in driving mood upwards or downwards, a position that requires further research.

Palmier-Claus, Dodd, Tai, Emsley and Mansell (2015) found a stronger direct effect of positive appraisals to activation without affect regulation strategies, suggesting the effect of appraisals on activation did not primarily occur through affect regulation (Palmier-Claus et al, 2015). This only partially supports Mansell's (2006) hypothesis that unhelpful strategies are used in response to appraisals, resulting in mood escalation. Palmier-Claus et al (2015) query whether their measure of affect regulation strategies (The Behaviour Checklist; Fisk, Dodd & Collins, 2015) does not accurately capture behaviours that may be employed in response to appraisals, resulting in a weaker effect. Another reason may be that behaviours used are unique to individuals and therefore difficult to measure (Palmier-Claus et al, 2015).

In depression, cognitive avoidance mechanisms are associated with intrusive memories and distress (Williams & Moulds, 2007), suggesting cognitive control strategies are important in maintaining intrusive memories in depression, similar to that of PTSD. Cognitive control strategies as a way to regulate intrusive images in BP, however, are unknown. Given that there are similarities in cognitive styles between BP and depression, it is possible that cognitive control strategies could play a similar part in BP. Research indicates that self and emotion-focussed positive rumination about positive affect is associated with greater lifetime mania frequency in BP (Gruber, Eidelman, John, Smith & Harvey, 2011), supporting the notion that cognitive control of internal states may impact mood, and needs further explanation in the context of the above mixed results.

Intrusive Images

Another significant theoretical proposal regarding the development of mania is the role of imagery as an emotional amplifier in BP (Holmes, Geddes, Colom & Goodwin, 2008). Holmes et al (2008) argue that because images induce a stronger emotional response than verbal thought (Holmes & Mathews, 2005), imagery may play a key factor in the escalation and de-escalation of mood in BP. For example, if a person had a positive image of themselves accompanied with positive mood-elevating beliefs and physiological arousal, this could result in amplified mood, resulting in action to work

towards these images as real events (Holmes et al, 2008). It has recently been found that people with BP report significantly more mental images than verbal thoughts, compared to people with unipolar depression (Ivins, Di Simplicio, Close, Goodwin & Holmes, 2014), and these images were more powerful and 'real' in their quality than verbal thoughts.

Different BP mood states have been found to be characterised by different types and qualities of intrusive memories and images (Gregory, Brewin, Mansell & Donaldson, 2010). In a hypomanic state, images were positive future-oriented events. All future-oriented images, whether positive or negative, were goal-oriented (Gregory et al, 2010). Supporting these findings, Ivins et al (2014) found that imagery within positive mood states for BP participants were positive 'flash-forwards' to possible positive future goals. Participants appraised them as evidence that positive outcomes would happen, describing a need to act on the scenarios they pictured. Compared to Palmier-Claus et al (2015), Ivins et al (2014) takes a more individual approach and ties the study into imagery, qualitatively suggesting that imagery and appraisals can create action in people with BP. This, however, is still only hypothesised and lacks research supporting this assumption.

Taken together, these results highlight the need to consider appraisals in response to imagery as an internal state, and behaviour in response to this in a BP sample. To date, mental imagery as an important internal state (Holmes et al, 2008), and extreme appraisals of imagery (Mansell et al, 2006) have not been compared relative to each other in people with BP. Ivins et al (2014) compared a BP sample to those with a unipolar depression, and as the authors conclude, they cannot exclude that these differences in positive flash-forwards are not as a result of a negative bias in unipolar depression (Ivins et al, 2014). The literature lacks a comparison of imagery in people with BP to the general population; currently it is unknown whether people with BP have more images in a positive mood state than the general population.

1.1 Aims and Objectives

This study aims to fill the gaps in the literature, specifically investigating whether people with BP have more mental imagery in a positive mood state than non-clinical controls, and whether imagery is appraised in an extreme way. The predictions from Mansell et al (2007) that BP will make more extreme, *conflicting* (positive and negative) appraisals of the image itself will also be investigated.

A final exploratory hypothesis aims to test the differences in behavioural responses to an image between groups. This is building on research from the role of cognitive control in depression (Williams et al, 2007) and results from Ivins et al (2014) that

images create the need for action. It is also an attempt to explore Mansell et al's (2007) hypothesis that once the individual makes an appraisal of an internal state they may make a behavioural attempt to control this internal state (e.g., rumination, dampening, intentional re-experiencing). This hypothesis from Mansell's theory is relatively untested and has been difficult to measure in other studies (e.g., Palmier-Claus et al, 2015).

Hypotheses:

1. People with BP will experience more intrusive imagery in a positive mood state than non-clinical controls.
2. BP participants will make more extreme (positive and negative) appraisals of these images than non-clinical controls.
3. BP participants will employ more cognitive controls strategies (rumination, suppression, dampening) to an image than non-clinical controls.

2.0 Methods

2.1 Participants

From December 2015 to April 2016, 23 BP participants (14 female) were recruited from *Bipolar UK* through an advertisement in their quarterly magazine (Pendulum) and support groups. 17 non-clinical controls (13 female) were recruited primarily from advertisements at the University of Bath. BP participants were recruited while in a euthymic state to minimise reporting bias. The inclusion criteria were as follows: (a) aged 18-65, (b) met the DSM-IV criteria of Bipolar I or II disorder (screened by the SCID) and (c) ability to use English to report intrusive imagery. Participants were excluded if they: (a) met the criteria for current mania or depression, (b) met the criteria for current PTSD, the main disorder where a diagnosis is characterised by the presence of intrusive images, and (c) had taken part in imagery based research in the past two weeks, to minimise priming as much as is possible.

Of the 23 BP participants, four were excluded as a result of current PTSD. In total, there were 19 BP participants (11 female). The age range for the BP participants 25-65, mean 47, and for non-clinical controls was 19-62, mean 31.

Participants received £5.00 as a 'thank you' for participation.

2.2 Measures

Information about participants' age, sex, education history, age of onset of BP and most recent manic/depressive episode (if relevant), current medications, and current

participation in treatment (including psychological interventions to establish whether imager was currently being investigated in intervention) were collected using the demographic information section of the SCID.

Current mania, hypomania or depression were measured using the:

- **Structured Clinical Interview for DSM-IV (SCID-I:** Spitzer, Williams, Gibbon & First, 1996). The mood and trauma modules were administered to establish diagnosis.
- **Internal State Scale (ISS;** Bauer, Crits-Christoph, Ball, Dewees, McAllister & Alahi et al, 1991). A measure of severity of BP symptoms, with four subscales; activation, well-being, perceived conflict and depression. Validated in both clinical and community samples (Bauer, Vojta, Kionsian, Altshuler & Glick, 2000; Bauer et al, 1991).

Imagery, appraisals and responses to images were measured using the:

- **Intrusive Imagery Interview.** Semi-structured interview based on schedules from previous research (Gregory et al, 2010). Intrusive images were defined, and participants were asked about images from a time they were in a positive mood state, using retrospective recall. This included rating frequency and intensity of images, interference with daily life, and on a range of emotions (e.g., sadness, euphoria, anxiety, and powerfulness). Please see Appendix J for full interview.
- **HAPPI** (Mansell, 2006). 50-item questionnaire measuring multiple, extreme, positive and negative appraisals of internal states. The mean of positive and negative items are calculated for analysis (see Kelly et al, 2012, for the process of developing positive and negative means). Previous studies have shown good psychometric properties (Kelly et al, 2011; Kelly et al, 2012). Internal consistency was $\alpha=0.85$ for the positive appraisals, and $\alpha=0.80$ for negative items (Kelly et al, 2012). In the current analysis, internal consistency for the total mean was $\alpha=0.95$, positive mean was $\alpha=0.86$, negative mean was $\alpha=0.78$.
- **Images HAPPI (iHAPPI).** A version of the above scale adapted for imagery; please see Appendix K. The original author of the HAPPI (Mansell, 2006), was consulted for this development. The following instructions were added; *please consider the images we discussed and ones like these that you might experience when feeling high and rate the following statements in relation to these*. In the current analysis, internal consistency for the total mean was

$\alpha=0.96$, the positive mean total was $\alpha = 0.96$, and the negative mean was $\alpha=0.90$.

- **Spontaneous Use of Imagery Scale** (SUIS; Reisberg, Pearson & Kosslyn, 2003). A 12-self-report trait measure of the spontaneous use of mental imagery. Previous studies have shown good psychometric properties (Reisberg, 2003). The internal consistency is reported to be 0.98 (Reisberg et al, 2003).
- **Responses to Positive Affect Scale** (RPA; Feldman, Joormann & Johnson, 2008). This scale measures emotional regulation in response to positive moods, on three subscales (dampening, self-focussed positive rumination, emotion-focussed positive rumination). Included in the intrusive imagery interview and adapted to be anchored to images discussed. Good internal consistency was demonstrated in an analogue sample (dampening, $\alpha=0.79$; self-focussed positive rumination $\alpha=0.71$; emotion-focussed positive rumination $\alpha=0.69$; Feldman et al, 2008). In the current analysis, the internal consistency of the self-focussed subscale was $\alpha=0.74$, the emotion-focussed subscale was $\alpha=0.25$, and the dampening subscale $\alpha=0.81$.
- **Response to Intrusions Questionnaire** (RIQ; Clohessy & Ehlers, 1999). 16-item questionnaire measuring rumination, suppression and numbing in response to intrusions. This was adapted to intrusive imagery and included in the intrusive imagery interview. Previous studies have shown good psychometric properties (Clohessy & Ehlers, 1999). The internal consistency of the subscales were as follows: rumination 0.31, suppression 0.72 and dissociation 0.40 (Clohessy & Ehlers, 1999). In the current analysis, the internal consistencies were as follows; rumination 0.72, suppression 0.82 and dissociation 0.54.

2.3 Procedure

Participants chose whether to participate over the phone or a face-to-face interview. Participants consented to the research. Initial screening using the SCID took place. Any uncertainties relating to diagnosis were resolved through discussion with the research supervisor, JG. Participants then completed the intrusive imagery interview, including the RIQ and RPA. Participants then completed the questionnaire pack.

Ethical approval was gained from the London Camberwell-St Giles NHS Ethics committee in September 2015, and from the University of Bath Ethics Committee in October 2015.

2.4 Statistics

Statistical analyses were performed using the Statistical Package for Social Sciences (SPSS) version 22.0 for Windows. Demographic characteristics between the groups were compared using independent t-tests and chi-squared comparisons.

The assumptions of the data were explored, and where these were violated they are highlighted. In analyses where only the non-clinical sample is not normally distributed (by Kolmogorov-Smirnov test), parametric analyses were considered appropriate given further observation of the p-p plots and histograms. In analyses where both the non-clinical and BP sample are not normally distributed, a mann-whitney u test is used. Where the Levene's Test was significant, the corrected statistic was used within the T-Test analysis. The hypotheses were tested using a one-way ANOVA (hypothesis one), a mixed model ANOVA (hypothesis two) and independent t-tests (hypothesis three). A priori power calculations were completed using G*Power. The estimated number of participant to achieve a power of 0.8, $\alpha=0.05$, and a moderate-large effect size of 0.4 (F Statistic), whilst conducting an ANOVA. A total sample of 52 (26 in each group) would achieve optimum power of 0.8. As there was no available study as a direct comparison for effect size, the aim of a moderate-large effect size was theoretically driven. As Holmes (2008) argues that imagery is a unique and significant element of BP, this suggests that imagery should have a large effect size in a comparison to a non-clinical sample.

3.0 Results

3.1 Demographic and symptom differences between groups.

The differences between groups were examined (see Table 1). There were no differences in symptom severity. Comparing ISS results to a similar sample (Mansell & Jones, 2006), the ISS scores of the controls were similar. The BP participants, however, scored lower on perceived conflict, depression and activation scores, and higher on wellbeing. According to Bauer et al's (2000) algorithm for symptoms using the ISS, the BP sample in this study were euthymic at the time of data collection. There was no significant difference of trait use of imagery (SUIS) between BP and non-clinical participants. Therefore, there is no difference between the groups in how much they experience imagery in their everyday lives.

The BP group were older, received less education, were more likely to be living alone, and were more likely to have received therapy in their lifetime.

Table 1: Demographic and clinical variables of BP participants

	Bipolar (N=19)	Non- Clinical (N=17)	Test used	DF	p
Age	Mean (SD) 47 (10)	Mean (SD) 31 (13)	F=16.3	1,34	<0.001*
Gender	N (%)	N (%)			
Female	11(57.9)	13 (76.5)	Fisher's exact test		0.302
Male	8(42.1)	4 (23.5)			
Relationship Status					
Single	8(42.1)	12 (70.6)	Chi-squared		0.164
Married/In relationship	7(36.9)	5 (29.4)			
Divorced/Separated	4 (21.1)	0 (0)			
Widowed	0 (0)	0 (0)			
Living Situation					
Living alone	9 (47.4)	1 (5.9)	Chi-squared		0.008*
Cohabiting (friends, family or partner)	10 (52.6)	16 (94.1)			
Level of Education					
GCSE/A-level	13(68.5)	0 (0)	Chi-squared		<0.001*
Undergraduate	5(26.3)	10 (58.8)			
Postgraduate	1(5.3)	7 (41.2)			
Employment Status					
Employed	13 (68.4)	9 (52.9)	Fisher's exact test		0.495
Unemployed	6 (31.6)	8 (47.1)			
Volunteering	10 (52.6)	4 (23.5)			
Received Therapy⁴					
Yes	15 (78.9)	5 (29.4)	F= 11.19	1,34	0.002*
No	4 (21.1)	12 (70.6)			
Past Episode of Depression					
Yes	19 (100)	9 (52.9)			
No	0 (0)	8 (47.1)			
Experienced a Distressing Event in their lifetime					
Yes	13(68.4)	8 (47.1)	F= 1.69	1,34	0.205
No	6 (31.6)	9 (52.9)			
Internal State Scale					
Perceived Conflict	102(85.2)	101.3(91.1)	T= -0.024	34	0.987
Wellbeing	167(61.3)	180(67.3)	T=0.59	34	0.559
Activation	97.3(93.8)	113.8(58.4)	T=0.678	34	0.503
Depression –median[range]	42.6(25.9) ^a 20[120]	30.7(36.4) ^a 10[120]	U=137		0.430
SUIS	41.21(8.82)	40.71(9.07)	F=0.029	1,34	0.867

⁴ Therapy refers to any type of therapy received; group, individual, Cognitive Behaviour Therapy (CBT), Cognitive Analytical Therapy (CAT), psychotherapy or psychoanalytical psychotherapy.

	Bipolar (N=19)	Non- clinical (N=17)	Test Used	DF	p
Current Psychiatric medication	N(%)	N(%)			
None	2(10.5)	15(88.2)	Chi-Squared		0.011*
mood stabilisers	5(26.3)	0			
antidepressants	1(5.3)	2(11.8)			
mood stabilisers+ antipsychotics	3(15.8)	0			
Mood Stabilisers + antidepressants	3(15.8)	0	T=-1.0 ^b	17	0.331
Mood Stabilisers, antipsychotics + antidepressants	3(15.8)	0			
Current reported illicit drug use					
Yes	1(5.30)	0(0)	T=0.627	33	0.535
No	17(89.5)	17(100)			
Current reported alcohol use					
Yes	12(31.6)	13(76.5)			
No	6(31.6)	4(23.5)			

*significant differences. ^aboth groups not normally distributed; mann-whitney u test completed. ^b equal variances not assumed; corrected statistic used

Regarding the BP participants, the mean time since diagnosis was 15 years (SD=13), ranging from 1 year to 44 year since diagnosis. The number of previous episodes of depression or mania was difficult to quantify within this sample. A number of participants found they were unable to count the amount of previous episodes of depression or mania; with 7 participants saying there were 'countless' episodes of depression, and 5 participants saying the same about mania. Aside from this, the amount of episodes ranged significantly from 3-25 previous episodes of mania, and 2-30 episodes of depression.

3.2 Differences in Imagery

Hypothesis one was tested using one-way ANOVA. There was a significant difference between the amount of spontaneous imagery people with BP experience in a positive mood state compared to controls ($F(1,34)=19.6; p<.001, \eta^2=0.35$). People with BP reported experiencing more spontaneous intrusive images in a positive mood state compared to people without BP.

Every participant (apart from one BP participant) retrospectively recalled at least one mental image from a previous positive mood state (see Table 2 for randomly selected images). BP participants experienced images in a more vivid way than non-clinical controls ($t(33)=-2.51, p=0.017$). These images were more likely to interfere with daily

life for BP participants ($t(18)=-6.37$, $p<0.001^5$). BP participants were more likely to feel euphoric ($t(33)=-2.64$, $p=0.012$) and powerful ($t(33)=-2.64$, $p=0.012$) in response to the image, there were no differences in other emotions (sad, helpless, anxious, fearless). BP participants were more likely to start doing lots of things in response to an image ($t(31)=-3.41$, $p=0.002$).

Both groups believed their images represented future goals, and believed at the time of experiencing them that they would help them achieve their goals. BP participants however, were less likely to believe with hindsight that the images did help them achieve their goals (Fisher's exact test, $p=0.006$).

Table 2: Examples of Intrusive images

Bipolar	Non-clinical controls
Flash forward to an upcoming Indian wedding event – I saw champagne, elephants walking around, bright colours, sparkles, lots of detail	Flashback to dancing with my friends at a music festival when thinking of spending time with my friends later. See the caravan we stayed in, and us dancing to the music
Seeing a future visit from my daughter – places we'll go to and things we'll do, in lots of detail	Planning ahead to go travelling – saw a virtual world of where I will be such as the beaches
Imagining a future motorbike racing event – see the circuit, see me winning the races and overtaking other drivers	Imagine venues I have played music at in the past – the audience, the buildings, when thinking ahead to future concerts

3.3 Differences in Appraisals

Comparing extreme appraisals between groups, there are significant differences between groups on all scales, with the exception of the positive mean from the original HAPPI (see Table 3).

⁵Equal variances not assumed – corrected statistic used.

Table 3: Between group comparisons on the iHAPPI and HAPPI.

	Bipolar (N=19)	Non-clinical (N=17)	Statistics		
	Mean (SD)	Mean (SD)	T	df	P
<i>iHAPPI</i>					
Positive	63.89(22.98)	36.51(19.76)	-3.770	33	0.001*
Negative	47(21.9)	13(13) ^a	-5.168	33	<0.001*
Total	54.73(21.09)	26.04(17.11)	-4.404	33	<0.001*
<i>HAPPI original</i>					
Positive	51.82(18.71)	44.92(14.99)	-1.211	34	0.234
Negative	42.78(16)	21.18(14.6)	-4.135	34	<0.001*
Total	45.73(16.01)	34.07(12.65)	--2.404	34	0.022*

^asignificant k-s test *significant result

A mixed model ANOVA was conducted to understand the differences between groups of extreme positive and negative appraisals about images in a positive mood state (iHAPPI). There was a significant main effect of bipolar diagnosis ($F(1,33)=22.51$, $p<0.001$). BP participants endorsed more positive and negative appraisals than controls. There was no interaction effect between group and positive and negative appraisals ($F(1,33)=1.03$, $p=0.317$). There is no difference between positive and negative appraisals within each group; BP participants endorsed a similar amount of positive and negative appraisals, as did the non-clinical controls.

Post-hoc independent t-tests revealed that BP participants endorsed significantly more positive and negative appraisals than controls, of images in a positive mood state⁶.

3.4 Differences in cognitive strategies

BP participants were more likely to use numbing responses and self-focussed rumination than non-clinical controls. The groups did not differ in their use of any other cognitive strategies when experiencing images in a positive mood state (see Table 4).

⁶ The same analysis was completed on the original HAPPI scale as a measure of control for the modification of the HAPPI measure. This analysis revealed very similar results to the above, with the exception of no difference found between BP and non-clinical controls on positive appraisals in the original HAPPI; please see Appendix L for these results.

Table 4: differences in raw scores, and statistics for cognitive strategy measures

	Bipolar (N=19)	Non-clinical (N=17)	Statistics		
	Mean (SD)	Mean (SD)	t/u	df	p
<i>R/Q</i>					
Thought Suppression	3.88(3.84)	3.35(3.42)	-.481	27	.634 ^b
Rumination	8.47(4.76)	7.47(3.61)	.691	32	.495
Numbing	4.35(2.37)	2.41(2.12) ^a	-2.515	31	0.017*
Total	16(6.69)	13(6.08)	-1.584	32	.123
<i>RPA</i>					
Emotion Focussed Rumination	12.24(2.28)	12.69(2.6) ^a	0.532	31	0.598
Self-focussed Rumination	9.94(3.11)	7.87(1.5) ^b	-2.45	23	0.022*
Dampening	14.82(4.99)	17.5(4.22)	1.66	31	0.108
Total	37(6.69)	38(5.2)	.594	31	.557

^a significant k-s test ^b equal variances not assumed – used corrected statistic *significant

4.0 Discussion

This study has shown for the first time that people with BP experience more intrusive positive images in a positive mood state than non-clinical controls, and make more extreme and conflicting (positive *and* negative) appraisals of those images. This cannot be explained by BP participants being a more ‘imagery based’ sample; no differences of trait use of imagery between groups were found. Furthermore, there were no differences in symptom severity, and therefore these results cannot be explained by current mood state. There are also few differences in cognitive control strategies, meaning these do not explain the differences in presence or appraisal of images between BP and non-clinical participants.

This adds to a growing body of literature which indicates positive flash-forward imagery is a distinct characteristic of positive mood in BP compared to other mood states in BP (Gregory et al 2010), and compared to other clinical groups (Ivins et al, 2014). This study for the first time indicates the role of extreme, conflicting appraisals attached to imagery as an internal state, supporting previous findings that both positive and negative appraisals are present in people with BP (Kelly et al, 2011). Furthermore, it

extends this to show that they are present about the *same* internal state whilst in a positive mood in people with BP (previously found in a non-clinical sample; Kelly et al, 2012), and these are significantly more extreme than non-clinical controls.

The results regarding cognitive control strategies (eg., rumination, suppression) are mixed. The only significant differences seen were that BP participants were more likely to use numbing and self-focussed rumination in response to an image than non-clinical controls. The numbing score, however, was lower than in other clinical groups (e.g., depression; Williams et al 2008; PTSD, Vossbeck-Elsebusch, Freisfield & Ehling, 2013), indicating this may not actually mean the BP participants use numbing a significant amount in response to the images. The scores for rumination and suppression were both lower than in PTSD, both strategies known to be associated with PTSD symptoms (Ehling & Ehlers, 2014) and play a part in maintenance of images in PTSD (Ehlers & Clark, 2000). This suggests that, in contrast to PTSD, a disorder characterised by the presence of images, cognitive control strategies do not play a part in the maintenance of positive images experienced in hypomania in BP or a positive mood state in a non-clinical population.

In relation to self-focussed rumination, this significant finding supports a similar finding by Gruber et al (2011) where people with BP were more likely to use self-focussed rumination than non-clinical controls. Gruber et al (2011) also found a difference in dampening, which was not supported here. However, in the present study, the questionnaire was adapted to be specifically related to imagery; therefore when investigating specific responses to an internal state, this effect is no longer significant, again suggesting this is not important in maintaining the role of imagery in BP.

These results add to the confusing picture that affect regulation is difficult to determine and measure in BP. As Palmier-Claus et al (2015) discuss, it could be that in this study the affect regulation behaviours could be unique to the individual and therefore difficult to define. Indeed, it is interesting that on one individual statement, *I start doing lots of things in response to the image*, there was a significant difference between BP and non-clinical participants. This is open to interpretation to each individual, however may represent a difference between groups in the amount of *activity* a person becomes motivated to do after seeing an image when in a positive mood state. This corroborates Ivins et al (2014), where individuals with BP described a need to take action following seeing an image. Interestingly, both BP participants and non-clinical controls held the belief at the time of seeing the image that it would help achieve goals. However, with hindsight the BP participants found this did not help them achieve goals whereas non-clinical controls did. This may in part explain the high level of negative appraisals associated with positive imagery compared to non-clinical controls, in that

hypomania/mania can often result in negative life consequences and reduce quality of life (MacQueen, Young, & Joffe, 2001).

4.1 Theoretical implications

The data supports Holmes' (2008) hypothesis that imagery is an important internal state for people with BP, compared to non-clinical controls. Furthermore, the presence of both positive and negative appraisals in the BP almost exclusively supports Mansell et al's (2007) hypothesis that internal states are appraised in *multiple* and *conflicting* ways. This is an important extension of research into the cognitive model of mood swings (Mansell et al, 2007), in that it highlights the same internal states can have *conflicting* appraisals, something which had not been tied to a particular internal state before.

Furthermore, it suggests that appraisals of imagery are at least as important as appraisals of other internal states. In fact, given there was a difference between BP and non-clinical controls of positive appraisals on the iHAPPI that was not found on the original HAPPI, it may be hypothesised the internal state of imagery is a more salient internal state that can access people's appraisals and high moods easier than other states. This is in support of both Holmes et al (2008), who highlight the unique features of imagery as an internal state in BP, and Mansell et al (2006), in that *multiple* and *conflicting* appraisals are important in BP. Given this sample are asymptomatic, the relationship to mood ascent and descent could not be tested, however previous research indicates extreme appraisals (as measured by the HAPPI) are independently associated with activation, depression and conflict (Dodd et al, 2011; Palmier-Claus et al, 2015).

4.2 Clinical Implications

These results show BP participants can identify, with hindsight, imagery, appraisals attached to these images, and that these images are actually not helpful in achieving their goals. Psychological interventions in BP often focus on relapse prevention when in a euthymic state (Lam, Hayward, Watkins, Wright & Sham, 2005), and findings from the current study may indicate new targets for intervention whilst euthymic.

Furthermore, imagery was found to be helpful in forming goals, yet with hindsight were not helpful in achieving these. Understanding this process could be helpful therapeutically in developing a new relationship with imagery. For example, if people with BP are conflicted over these images, this may result in difficulties with planning goals, resulting in lower mood. Therefore, developing a different relationship with imagery may result in a different experience of imagery and mood in that they could be

used more helpfully in goal pursuit in BP. For example, understanding the issue that with hindsight, the images themselves are not helpful in achieving goals may potentially be significant in understanding the conflicting relationship with goals and subsequent mood variation. Imagery as an internal state is transdiagnostic, and success has been shown in targeting imagery in cognitive therapy for other disorders (Hackmann, Bennett-Levy & Holmes, 2011), and there may be benefit in extending this knowledge into imagery in BP. For example, if a person with a diagnosis of BP could develop a more helpful relationship with their images whilst in a positive mood state, this potentially could have implications for goal pursuit and mood escalation.

4.3 Limitations

There are a number of methodological limitations to this study. Participants used retrospective recall when answering questions on imagery in a positive mood state. Many participants had to go back in time to recall an experience of being in a positive mood state, and this time was longer than other research (Ivins et al, 2014). The BP participants were more likely to go back over one year, and the non-clinical participants were more likely to go back to between 6-12 months. The interview may have been subject to response bias. However, participants continually reported that their imagery experience was being captured by the interview when asked about the interview process. Most non-clinical controls recalled an emotionally salient time for them, such as graduating from their degree. It is well known that memories from emotional salient events are more easily recalled than others (Baddeley, 1997), and should be more reliable.

It is, however, difficult to discern whether the positive mood states recalled by BP participants were of hypomanic/manic episodes as participants chose a 'positive mood state' (to ensure the interview was the same for BP and non-clinical controls). Imagery characteristics described by the BP participants may be from hypomanic, manic, or general positive mood states. However, considering differences were found between groups, even if BP participants were not recalling from a hypomanic episode, this shows there are differences in positive mood compared to non-clinical controls. This is a similar difficulty reported by other researchers investigating imagery in different mood states in BP (Gregory et al, 2010; Ivins et al, 2014). The research lacks a prospective, real-time investigation of mood states in BP.

There are some differences between groups, which reduces the validity of these results. The control sample were younger in age and had a higher level of education, for example. Furthermore, half of the non-clinical controls previously had an episode of depression in their lifetime (as screened by the SCID-I). However, it is well established

that people that have experienced depression in the past do not differ in their attributional negative biases compared to people that have never been depressed (Dohr, Rush & Bernstein, 1989). Further research comparing BP to non-clinical controls would benefit from age and education-matching the controls, and this was difficult to accomplish in this particular study.

A further limitation of this study is that participants were self-selecting, which may mean that the prevalence of intrusive images is not completely representative of the general population, both that of BP and non-clinical controls. However, given both samples were self-selecting, this would not account for the differences between groups, and also the differences between appraisals of the images.

4.4 Future Directions and Research Implications

This research has a number of implications for future research. The different results between the original HAPPI and iHAPPI may indicate that comparing appraisals of imagery to appraisals of other internal states (e.g., verbal thoughts, increased heart rate) would be an important extension of this research. For example, it may be that imagery *does* access appraisals easier than other internal states as measured by the HAPPI, or that simply tying the HAPPI into a particular internal state (the type of which does not matter) means that it more easily accesses these appraisals in a BP sample. Research investigating this would help determine the relative importance of imagery to other internal states. It would also aid further investigation of the relative significance of Holmes' (2008) hypothesis of imagery as a more significant internal state to Mansell et al's (2007) hypothesis that the appraisals are more important than the type of internal state.

These results show that imagery can be helpful in forming goals. The finding that with hindsight, BP participants found the images were not helpful in achieving their goals is interesting, and may have significance in the conflict experienced by BP participants (i.e., the negative appraisals of positive imagery based on past experience of mania/hypomania). Future research into the relationship between imagery and goals would be beneficial in understanding whether this affects goal pursuit in BP. Furthermore, investigating the conflict of the images being unhelpful in the long-term may help understand the relationship between the presence of both positive *and* negative appraisals of imagery as an internal state.

4.5 Conclusions

In conclusion, the present research provides the first evidence for the presence of extreme, conflicting appraisals about spontaneous intrusive imagery in a positive mood state in BP, and that these occur significantly more in a BP sample compared to non-clinical controls. This is also not explained by current mood state, or trait use of imagery. These results support both Mansell et al's (2007) integrative cognitive model of mood swings, and also Holmes' (2008) hypothesis that imagery is a unique internal state in BP. Future research is needed to establish the relative importance of imagery over other internal states, and investigating the relationship between imagery and goal pursuit in BP.

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Executive Summary

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Investigating intrusive imagery, appraisals and positive mood states in Bipolar Disorder

Why the study was conducted

Bipolar Disorder (BP) has historically been understood in medical terms, and understanding BP from a psychological point of view has been lacking. In recent years, there has been research into the possible psychological reasons for changes in mood in people with BP. Recent research indicates the role of 'intrusive images', that is, things you see in your minds' eye without obvious explanation, are important in BP (Holmes et al, 2008) because they can access emotions quickly and easily. Mansell et al (2007), however, argue that it is the way people with BP make sense of internal states, that is information from inside the body (such as heart rate, thoughts, or images) affects mood. For example, if a person interprets their heart rate in an extreme and conflicting way, and meaning something significant about themselves, they might try to manage this, leading to an increase or decrease in mood. Studies have shown that people with BP have more of these extreme ways of making sense of internal states than people without BP, and they are linked to mood.

These two theories had not before been tested against each other. Intrusive imagery in people with BP had not previously been compared to a non-clinical population (i.e. someone without BP and other mental health conditions), so it was not known whether people with BP had more intrusive images than non-clinical participants, in a positive mood state. Also, the way people with BP make sense of intrusive images as internal states has not been investigated. The aim of this study was to investigate imagery in a positive mood state in people with BP, compared to non-clinical participants, and to investigate the extreme appraisals or interpretations of these images. The primary research question was to determine whether people with BP have more intrusive images than non-clinical participants, and if they made more extreme appraisals of these images.

What the study involved

Between December 2015 to April 2016, 19 participants with BP and 17 non-clinical participants took part in this research study. Participants who took part completed an interview about a previous time they were in a positive mood state, and were asked about any intrusive images they may have experienced in this time. After this,

participants completed some questionnaires looking at extreme appraisals of these images.

What the study found

Participants with BP experienced more intrusive images in a positive mood state than non-clinical participants, and this was not explained by generally having more images in everyday life. Participants with BP also made sense of these images in both extreme positive *and* negative ways more than non-clinical participants.

Conclusions

This study has shown that images occur more in people with BP than non-clinical participants. This builds on other research which shows that people with BP have more images than people with depression (Ivins et al, 2014), which may indicate that images are a unique and important state for people with BP. For the first time, this study has shown that people with BP make extreme positive *and* extreme negative appraisals of the specific internal state of imagery.

What were the limitations?

The main limitation of this study is that people retrospectively recalled the time they were in a positive mood state and the images at that time. This may mean that not all details are captured, and that some participants may not have accurately remembered. It is important to note, however, that participants often reported that the interview accurately captured their imagery experience. The research lacks a prospective, real-time investigation of mood states in people with BP.

There are also some differences between the groups; the non-clinical sample was younger in age and had a higher level of education, for example. This may have affected the results, and future research should try to age and education match the two samples, something which was difficult to accomplish in this study.

Implications for Theory and Research

This study supports both Holmes et al's (2008) and Mansell et al's (2007) theory. It indicates the role of imagery as an important internal state in BP (Holmes et al, 2008), and importantly, also almost exclusively supports Mansell et al's (2007) theory, in that people with BP make *conflicting* positive *and* negative appraisals of these.

To understand whether imagery is more important than other internal states (such as verbal thoughts or heart rate), the frequency of imagery should be investigated in comparison to these other internal states in BP. To understand whether imagery

activates these extreme conflicting appraisals more than other internal states, these appraisals of different internal states should be compared.

Connecting Narrative

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Main Research Project

During my training, I was keen to learn something new, and something I knew little about, and thought my main research project would provide me with a good opportunity to do this. My research skills were in their infancy at the beginning of training, and therefore I felt an important learning need was having good research supervision. I also wanted to be interested in the area to be able to keep me going to the end of the project. After our bipolar teaching from Dr James Gregory, I remember being surprised at the lack of development of understanding of the psychological mechanisms of bipolar, compared to other mental health difficulties. I approached James to discuss his research ideas, and found myself intrigued to continue in this research field. I also felt James had good research experience and was willing to supervise my project in a way that encouraged the development of my research skills from the beginning.

Over a number of discussions with James, and a thorough search of the literature, I decided to investigate imagery, appraisals and behavioural responses to imagery in bipolar disorder. A woman with personal experience was also involved in the development of ideas, and I was very grateful for her input. Her personal understanding of bipolar was invaluable in shaping the design of our study. Through involving her, I knew that the areas of study were of interest to someone with bipolar, and that the interview schedule could be answered with retrospect. I enjoyed learning from her, and found this process was fitting with my clinical experience of needing to listen to personal experience to truly understand something and inform development of your work. Dr Warren Mansell, an expert in the area, also became involved at this time, consulting on the ideas and design of the project. Warren was involved through Skype meetings over the course of the project, and I found his expertise in the area very useful for the development of the project.

The aim was to understand whether imagery was an important internal state in bipolar disorder compared to non-clinical controls, and whether people make extreme appraisals of these images, testing Mansell et al's (2007) cognitive model. We decided to modify the interview schedule from James' previous research and conduct a semi-structured interview with questionnaires. At this point, another colleague (Rosie Oldham-Cooper) was also recruiting in bipolar and we developed some of our ideas together. Once the proposal was passed, I applied for and obtained ethical approval for the study. I found the IRAS process one of the most challenging of this research experience. I felt under pressure to keep to timescales within the university, yet also trying to fully understand what I was doing before I put the project into ethics. I found defending my work difficult at this stage, because I was still just understanding the

mechanisms under study. James was encouraging and supportive at this point. This was helpful in developing my understanding of the fine details of my research process.

I found data collection an interesting and challenging journey. Rosie and I gained help from an undergraduate research student (Andrea Pintos) for the development of online questionnaires (Bristol Online Survey). Andrea also was helpful in putting up advertisements across campus at the University of Bath. I was also able to place an advertisement in Bipolar UK's magazine and found this an invaluable recruitment source. As soon as the advert went out, I received a large number of participants and found Bipolar UK was sufficient for recruitment. This was an interesting learning point for me, because I had found it a struggle to engage the NHS teams I was initially planning to recruit from. I felt this was at a time when teams were under a lot of systemic change and pressure, and wonder whether this affected NHS recruitment at that time.

The actual process of recruitment with my participants is something I really enjoyed. I found my bipolar participants motivated and passionate to see change and challenge the status quo. I found this inspiring, being able to hear their stories and also gather data for my project. I found the further along I went, the more passionate I became of helping these stories be heard. The main challenge I found with this process was being a 'researcher' rather than a 'psychologist', hearing very difficult stories yet keeping on track with the interviews. I often felt that I had been able to connect with participants whilst not switching from 'researcher' to 'psychologist'. I occasionally had feedback from participants that they had found the interview rewarding and helpful for themselves, and that I had a gentle and curious approach to the interviews. I found this feedback incredibly helpful as I was so new to this process, and I was often touched by the kind words of my participants. I was certainly sad when I came to the end of data collection; on reflection, I found this part of my main research project to be the most rewarding.

Data analysis itself was aided again by Andrea, who inputted my data into SPSS for me. This was incredibly helpful, as at that point in time I was very busy and behind with other projects. The data analysis process was a challenging one, because once I reviewed the amount of data I had, I realised how much there was. This meant it was difficult and overwhelming at a time when I was close to the end and running out of energy. I found James was very helpful at this time, keeping my interest in the results and helping me make sense of the results. Warren read through the results at this time, and I recognised both Warren's and James' excitement at the research findings. I was yet to feel that, because I was looking towards finishing. Both Warren and James' enthusiasm at these findings, however, helped me find my way through to the end, and

find my own enthusiasm for them too. I found that, as our results fit with the theories we were investigating, it almost brought the work to full circle, and certainly has allowed the voices of my participants to be heard.

In terms of my own interest in bipolar, I found passion, enthusiasm, and a strength in my participants that has added to my interest in learning from those who have experienced these difficulties from a personal perspective. I found this echoed my experience of working with someone with personal experience to help design the project. This links into my initial aim of learning something new, and I feel I have gained so much from this experience. I hope to continue this learning into both my clinical work and future research. I also have become very interested in imagery as a transdiagnostic process, and have increasingly brought that into my clinical work, reflected in my final case study of imagery re-scripting in intrusive memories in a man with autism. I hope to be able to continue to investigate imagery in the future.

Service Improvement Project

My main research project was an opportunity to explore something new to me, and I found I wanted to build on my previous interests and experiences prior to training in my other projects. I had previously worked in older adult services and had a strong interest in this field. During this work I had noticed difficulties in managing risk, and occasionally differential attitudes towards risk in older adult clients compared to younger adults. After spending time on my working age adult placement and moving into my older adult placement, I continued to notice differences in the difficulties in managing risk and felt this needed to be investigated. Therefore, the idea for my SIP developed whilst on my older adult placement, wanting to address this ongoing issue I was noticing. This was considered in the light of changing to ageless services, which highlighted the need to continue to recognise the differential presentations between older and younger clients. I raised this idea with my older adult supervisor, Paul Whitby, who agreed with this and helped develop my project idea.

My initial internal supervisor was Dr Falguni Nathwani. Falguni had previous experience in older adult services and was keen to supervise this project. Her enthusiasm and research knowledge helped develop my ideas further. After multiple discussions with both Falguni and Paul, we decided to settle on a focus group methodology, interviewing staff members with experience about managing risk and improving practice in older adult services, to be able to develop recommendations for change. This was in light of the research area being under-researched, and therefore gathering knowledge was essential to be able to develop ideas for improving practice as a first step. At this stage, a stakeholder analysis was also conducted with older adult

psychologists and CPNs in the region, who helped develop the interview schedule and confirmed the need for a focus group over individual interviews. Dr Anthony Harrison (suicide prevention lead Avon and Wiltshire Mental Health Partnership NHS Trust; AWP) was also involved at this stage, and was keen for this project to go ahead. I then sought ethical approval from the university and research and development at AWP, both of whom passed the study with few amendments.

The experience of recruitment was a positive yet challenging experience. On reflection, the transitions into ageless services was creating stress and strain on the older adults systems, meaning the staff members were particularly concerned about their clients, and were overwhelmed with how much work they had to do at that time. This affected the interviews, the majority of comments about improvements were actually about barriers that were currently in their way, and in some sense there was hopelessness around change. I remember finding this difficult to manage as I felt it was important these views were being captured, yet did not completely answer my research questions. Reflecting on this, I felt I learnt about the complexity of both focus groups, and also systemic change and how this can influence research. I hope to take this knowledge forward in future research work.

I previously had little experience in qualitative research, and I found I learnt about the approach quickly through this project. I found this sparked my interest in qualitative research, and found it with my experiences of wanting to find a way of learning from people with experience, and allowing in-depth perspectives to be told. I really enjoyed the data analysis stage. I found this challenging at first, feeling overwhelmed with the amount of data in front of me. However the further I went into the analysis, the clearer it became and I found this rewarding. At this point, a colleague of mine (Clare Dixon) also analysed the data and we compared results, to corroborate my analysis process. I found this support helpful, as before this, I could not be sure whether it was mostly within my own interpretation.

As I came to write the results, Falguni left the university and became an external supervisor. Dr Jo Daniels took over the supervision of this project, and her main role was to give feedback on my draft work. Jo was helpful in adding an outsider perspective and a fresh pair of eyes to my work, which at that point, had almost finished.

Disseminating the results and recommendations of this project has proved a challenge for me, and I feel I have learnt through this process. Anthony was keen to hear the results of this project, and met with me to discuss the recommendations. He was happy to take these forward to the suicide prevention board, and tie some of these findings

into a project he was running into self-harm in older adults. The teams, however, were harder to engage in receiving feedback. At this point, Jo was off work and I myself had to take time off. This impacted the feedback, in that it was difficult to keep in contact with teams. Paul Whitby at this point was not completely involved in the project either, and therefore I lacked direction within older adult services to be able to feed these recommendations back and develop them further. The aim of the project was never to see the recommendations to fruition, as the research in this area is in its infancy and was beyond the scope of this project, yet I am in contact with the psychologists who took part in this research, and plan to provide further feedback on the recommendations.

I have found this challenging, as I am keen to help these recommendations be taken further forward than they already have been. I feel they are worthwhile and shed light on something which previously hadn't been in this detail. Reflecting on this, I have learnt to be more assertive in communication with teams and research colleagues where I feel I needed support in dissemination. I am looking forward to meeting with the psychologists who have participated in this research to take these recommendations further.

Literature Review

My literature review was also a chance to build on my previous interests and experiences but with a different focus. My experience with older adults also included working in a stroke service. During my work as an assistant, I had noticed the shortcomings of a standard Cognitive Behavioural approach in post-stroke psychological interventions. As an assistant I had little knowledge to be able understand the difficulties with applying the CBT approach, but I was keen as a trainee with developing skills to learn more about this area. I was passionate to play a part in identifying some of the gaps in the literature and clinical practice, and considering how this could be taken forward.

My initial supervisor was Dr Andrew Medley, a clinical psychologist with interest in the traumatic brain injury (TBI) field. My original premise that CBT is not wholly effective in stroke care involved a thorough exploration of the available literature to notice gaps in understanding new ways to conceptualise psychological difficulties after stroke. This led to an investigation of the psychological adjustment after stroke literature. Andrew was also passionate about the third-wave approaches and their application to the TBI, with a growing evidence-base in the application of compassion-focussed approaches to the TBI field. This led to the idea of applying this approach to the stroke literature. At this point, Andrew left the university. I found this challenging, as I had submitted and

passed my proposal for a compassion-focussed review, however had little knowledge about this approach myself.

Lorna Hogg took over the supervision of this project due to her interest in the compassion focussed approach. At this point, Lorna helped design the rationale for this approach and I felt the literature review was taking shape. Lorna's expertise for my literature review was in the compassion focussed approach instead of the area of 'stroke' as a whole. However, the further into the rationale of this review I went, the more we realised there was not enough literature for a full critical literature review into this approach. I found this stage very challenging and felt I had lost a lot of work through this change. It felt like a 'fine line' to decide whether to continue with the question or not. I made the decision to change because I did not feel comfortable in continuing with the idea, and felt like it was not my question to ask. I was very grateful for Lorna's support at this time, because I felt like I was in a fog and unable to find my way out. Lorna had fresh eyes to the stroke literature because of her unfamiliarity with the area, and helped me be more objective with my approach.

At this point, I went back into the literature to try to find a new idea. After a few different ideas, I found a research question with enough papers to make the review possible. The literature review's final focus was the role of social identity in post-stroke psychological adjustment, a qualitative synthesis. I felt this research question truly did fill the gap in the psychological adjustment after stroke literature and felt this was worth pursuing.

Conducting a qualitative synthesis was a very enjoyable process which I would not hesitate to do again. This further cemented my initial learning of qualitative approaches through my SIP. I have continually found this approach helpful, and I appreciated the opportunity to learn and develop these skills in a different way. This was a steep learning curve, support by Dr Cathy Randle-Phillips as well as Lorna, due to her knowledge in qualitative research methods. I found the support from Cathy and Lorna invaluable in this learning journey through a complex qualitative project, and using a theory I knew little about.

This synthesis was supported by two colleagues (Paula Robinson and Beth Jones) who independently rated 20% of my studies. Through completing a meta-ethnographic approach, I have learnt invaluable skills about methodologically rigorous qualitative research, and feel passionate about being able to implement this in future research practice. I was pleased to be able to use a qualitative approach in my literature review, as I felt this continued to echo my passion for enabling in-depth exploration using the voice of people with experience. This was a good comparison to my main project,

where I had originally found my interest in exploring people's experiences through research processes. Whilst completing my literature review, I was also coming to the end of my main research project. Reflecting on the balance between quantitative and qualitative research, I have found both of these projects have actually allowed for stories and narratives to be explored in very different but useful ways. I hope to continue to learn the balance between quantitative and qualitative in my future work.

Case Studies

Completing case studies on each placement has increasingly developed my awareness of the links between theory, evidence and clinical practice. As I put my case study portfolio together, I was able to notice my development in clinical and research practice, noticing the difference in formulation and complexity through the five case studies. Reflecting on that change was helpful, to be able to see my development of both clinical skills and research knowledge applied to clinical work. I have always enjoyed writing my case studies, an opportunity to consider clinical work in depth, and the chance to reflect on the process of therapy. Completing two experimental studies has also helped me develop more structure to my clinical work and consider measurement very carefully. I hope to be able to use this structure in my future clinical work, particularly in learning disabilities practice where future research is lacking in develop therapeutic interventions.

Acknowledgements

Research

Thank you to my research supervisors for their ongoing support and advice over the ups and downs of these three years. In particular, I'd like to thank James Gregory, Falguni Nathwani and Lorna Hogg for your encouragements and enthusiasm throughout. I would also like to thank my research participants. I was profoundly influenced by your stories, reflections, and abilities to challenge the status quo, thank you.

Thank you also to Cathy Randle-Phillips. Cathy, thank you so much for listening to me, reminding me of the big picture, and providing me space to understand, reflect, and be myself. Thank you to my clinical tutor, Paul Salkovskis, for saving the day when needed, and for believing in me.

Placement supervisors

My placement supervisors have been encouraging throughout the course. Thank you for providing me with inspiration, and believing in me when I have not been sure in myself. In particular, I'd like to thank Jon Freeman, Kate Allez, Rachel Davies, Jon Cash, Claire Delaney, Olivia Donnelly and Alex Westcombe. Claire, Jon, Alex and Olivia – thank you for seeing me through my toughest year yet, and allowing me to see I can do this job, even with the challenges along the way.

For all of those I have seen for therapy, I am grateful. For each of you, you have shown me the true meaning of vulnerability, and I have learnt so much from you.

Friends and Family

I could not have done this without the support of my friends and family. To my friends, thank you for helping me keep my head above the waves. Thank you for continuing to remind me what is important and giving me perspective. To my family, for the journey we have all taken in these three years, I am so grateful to you all for being here and believing in me no matter what.

Last, but certainly not least, to the cohort. There is no journey like this one, and thank you for sharing it with me.

Appendices

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June 2016

Appendix A: Author guidelines for Critical Literature Review

About this journal: Disability and Rehabilitation

Disability and Rehabilitation is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Disability and Rehabilitation accepts the following types of article: Reviews, Research Papers, Case Studies, Perspectives on Rehabilitation, Reports on Rehabilitation in Practice, Education and Training, and Correspondence. Systematic Reviews should be submitted as "Review" and Narrative Reviews should be submitted as "Perspectives in Rehabilitation".

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- Authors who wish to be **identified** should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the "Main Document".

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We also refer authors to the community standards explicit in the American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct.

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

For a review paper of 10 or more pages in length please include a table of contents, with all major headings and subheadings included in the text.

Word count

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

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Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use any spelling consistently throughout your manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

For tables and figures, the usual statistical conventions should be used.

Drugs should be referred to by generic names. Trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

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2. A structured abstract should cover (in the following order) .
3. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.
4. **Graphical abstract.** This is an image to give readers a clear idea of the content of your article. It should be a maximum width of 525 pixels. If your image is narrower than 525 pixels, please place it on a white background 525 pixels wide to ensure the dimensions are maintained. Save the graphical abstract as a .jpg, .png, or .gif. Please do not embed

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 - Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
 - Reconstructive surgery is a technique available to this group.
 - In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
 - People with MS have complex reasons for choosing to exercise or not.
 - Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.
8. **Funding details**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the <Funding Agency> under Grant <number xxxx>. *For multiple agency grants*: This work was supported by the <Funding Agency 1> under Grant <number xxxx>; <Funding Agency 2> under Grant <number xxxx>; and <Funding Agency 3> under Grant <number xxxx>.
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committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

Consent

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Appendix B: Table of all studies in Critical Literature Review

No.	Authors	Country	Aim	Participants	Methodology and analysis	Data collection	Analysed themes	Quality Rating
1 HQ	Anderson and Whitfield (2012)	Canada	Understand the ways in which family, social and community affect stroke survivors participation in meaningful activities	9 participants (6 men) Age range: 53 – 64 Time since stroke: unknown at time of data collection	Semi-structured interviews Grounded theory	Participants interviewed once	Fighting for a valued position post-stroke	8
2	Boylestein, Rittman and Hinojosa (2007)	USA	To understand how metaphors help explain stroke recovery (as a part of a wider study)	29 participants (all veterans, all male) Age range: 40 - 84 Time since stroke at first interview: 1 month	Semi-structured interviews Grounded theory	Participants interviewed at two different time points; 1 and 6 months post-stroke	Stroke recovery is a war	6
3	Burton (2000)	UK	To develop understanding of how stroke survivors experience their stroke and recovery	6 participants (2 male) Age range: 52 – 81 Time since stroke at first interview: not reported, but interviewed whilst in hospital	Semi-structured interviews Grounded theory	Participants interviewed at 1 monthly interviews for 1 year after stroke. Total number of interviews – 73	Changing roles Reflections on previous life	6.5
4	Clarke and Black (2005)	Canada	Investigating quality of life after stroke	8 participants (3 men) Age range: 60 – 81 Time since stroke: 7 months – 9 years	Focussed interview technique	Participants interviewed once	The effects of stroke on sense of self and identity	7
5 HQ	Crowe, Coen, Kidd, Hevey,	Ireland	To understand the emotional effects of stroke	10 Participants (6 male) Age range: 53 - 80 Time since stroke: 6 weeks	Semi-structured interviews	Participants interviewed once	The loss of self	9 106

	Cooney and Harbison (2015)			to 12 months	IPA			
6 HQ	Erikson, Park and Tham (2010)	Sweden	To investigate the meaning of being with others in different places over the course of 1 year post-stroke	9 participants (6 males) Age range: 42 – 61 Time since stroke at first interview: 1 month	Semi-structured interviews Grounded theory	Participants interviewed at 1, 3, 6 and 12 months after stroke	Not recognised as the person I am	8
7 HQ	Eriksson and Tham (2009).	Sweden	Identifying how occupational gaps are characterised in people's experiences of performing everyday activities after stroke	4 Participants (3 men) Age range: 50 - 61 Time since stroke at first interview: 1 month	Semi-structured interviews Empirical Phenomenological psychological (EPP) method	Participants interviewed 4 times in first year after stroke	Searching through a new self through doing	8.5
8 HQ	Fallahpour et al (2013)	Iran	Understand the lived experience of stroke survivors in Iran	8 Participants (4 male) Age range: 45 - 68 Time since stroke: 5 – 26 months	Semi-structured interviews (EPP) method	Participants interviewed once	I cannot do activities as before I am not the same person – discovery of a different self I am not living my life	8

9	Gallagher (2011)	Canada	Examine the emotional process of stroke recovery	9 participants (gender not reported) Age range: 42 – 82 Time since stroke: 6 months – 4 years	unstructured interviews Grounded theory	Participants interviewed once Focus group at end of study to clarify findings		7
10 HQ	Horne, Lincoln, Preston and Logan (2014)	United Kingdom	Explore the meaning of confidence to stroke patients to inform the development of a measurement tool	10 Participants (5 male) Age range: 32 - 86 Time since stroke: 18 months – 9 years 10 months	Semi-structured interviews IPA	Participants interviewed once	Identity loss Social confidence Role confidence	9
11 HQ	Kitzmuller, Haggstrom and Asplund (2013)	Norway	Understanding the significance of the long-term influence of bodily changes on the perception of self after stroke	23 participants (14 male) Age range: not reported Time since stroke: 3 – 25 years	Semi-structured interviews Phenomenological hermeneutic approach	Participants interviewed once	Living in a body that is not me Living with an altered perception of self	9
12 HQ	Kouwenhoven, Kirkevold, Engedal and Kim (2011)	Norway	Understanding the lived experience of stroke survivors suffering from depression in the acute phase	9 participants (3 male) Age range: 30 – 85 Time since stroke: 4 – 7 weeks after stroke	Semi-structured interviews Hermeneutic phenomenological analysis (Ricoeur)	Participants interviewed once	Losing oneself	9.5
13 HQ	Kuluski, Dow, Locock, Lyons and Lasserson (2014)	UK	To understanding the experience of stroke among young people and the ways they learn to cope	17 participants (6 male) Age range: 28 – 55 Time since stroke: 1 – 22 years	Semi-structured interviews Directed content analysis	Participants interviewed once	Altered sense of self Adapted sense of self	8

14	Kvigne, Kirkevold and Gjengedal (2004)	Norway	Explore how female stroke survivors experienced their life after a stroke	25 participants (all female) Age range: 37 – 78 Time since stroke at first interview: 6 weeks	Semi-structured interviews Phenomenological method (Giorgi)	Participants interviewed 3 times during first 18 months after stroke	Attempting to maintain control of valued female roles and accept help Negotiating relationships on equal terms	5.5
15 HQ	Martinsen, Kirkevold and Sveen (2012).	Norway	To explore how living with the consequences of a stroke impacts on family life in the late recovery phase (6 months + after stroke)	22 participants (15 male) Age range: 22-61 Range of time since stroke: 6 months – 9 years	Semi-structured interviews Hermeneutic Phenomenological analysis	Participants interviewed once	Struggling to re-enter the family	9
16	Murray and Harrison (2004).	United Kingdom	To investigate the meaning and experience of being a stroke survivor	10 participants (4 males, 6 female) Age range: 38-81 Range of time since stroke: 4 – 20 years	Semi-structured Interviews (five conducted face to face, 5 over email) IPA	Participants interviewed once with face-to-face interviews The email exchanges took place on an average 8.4 exchanges	Disrupted embodiment and loss of self	6.5
17 HQ	Taule & Rahim (2014).	Norway	Explore the experiences of mild stroke survivors in the context of Early Supported Discharge (ESD)	8 participants (4 male, 4 female) Age range: 45-80 6-8 months post-stroke	Semi-structured Interviews Interpretive Design Analysis	Participants interviewed once	Life changed existentially (self-perception – am I still good enough?)	9.5

18 HQ	Thompson and Ryan (2009)	UK	To provide insight into the experience of stroke recovery within spousal relationships	16 participants (9 males) Age range: 33 – 78 Time since stroke: 2 months – 4 years	Semi-structured interviews Content data analysis	Participants interviewed once	Dichotomies of pre- and post-stroke self Perceived loss of control	9
19	Wolfenden and Grace (2012)	Australia	Explore the experiences of young, higher functioning stroke survivors in re-establishing identity and returning to work	5 participants (all female) Age range: 34 – 44 years	Semi-structured interviews critical interpretivist approach	Participants interviewed once	Participant perceptions of identity Identity threatened Resumption of life roles and responsibilities One enduring identity	6

No.	Authors	Country	Aim	Participants	Methodology and analysis	Data collection	Analysed themes	Quality Rating
20	Dowswell, Lawler, Dowswell, Young, Forster & Hearn (2000)	UK	Provide a detailed description of psycho-social difficulties post-stroke and consider the benefits of including qualitative results to a quantitative trial	30 stroke survivors 15 caregivers Gender not reported Age range: not reported. Time since stroke: 13 – 16 months	Semi-structured interviews (same interview schedule for caregivers and stroke survivors) Method of analysis not discussed	Separate interviews for caregivers and stroke survivors Amount of interviews not reported	Social activities, psychological and physical wellbeing	5

					Interviews for caregivers and stroke survivors were analysed separately.			
21	Ellis-Hill, Payne & Ward (2000)	UK	To explore the perceived life and identity changes after a single stroke	8 stroke survivors (5 male) and their partners Age range: 56 – 82 Time since stroke: not reported	Semi-structured interviews Life narrative approach All interviews were separate apart from one couple who were interviewed together	Each participant interviewed in hospital, at 6 months and 1 year after stroke. Total of 24 interviews	Fundamental change Social self-body relationship	7.5
22 HQ	Musser, Wilkinson, Gilbert & Bokhour (2014)	USA	To understand the lived experience of individuals with aphasia and the trajectory of the effect on their social identities.	12 stroke survivors (10 male) Age range: 46 – 71 Time since stroke: 1 – 28 years	Semi-structured interviews Grounded theory Partners present in majority of interviews. Due to nature of communication difficulties, some analysis relied on conversational collaboration with partners. Ranged from clarification to	Interviews occurred at 5 time points; initial interview, 3, 6, 12, and 18 months after initial interview.	Occupational identity Relationships and family roles Social identity	9

					introducing new topics – analysed separately.			
23	Palleson (2014).	Denmark	Identify, from a long-term perspective (5 years), stroke survivors self-identity, their views on disabilities and how they manage life after stroke	<p>15 participants (10 male, 5, female) Age range:42-84</p> <p>Caregivers were present at 6 interviews. In most cases, they supplemented memories when stroke survivor asked for this. In a few cases they presented a different view to the stroke survivor resulting in points of discussion</p> <p>Approx. 5 years post-stroke</p>	<p>Semi-structured interviews</p> <p>Phenomenological method (Giorgi)</p>	Participants interviewed once	Self-Identity	7.5
24 HQ	Parr (2007)	United Kingdom	Track the day-to-day life and experiences of people with severe aphasia after stroke	<p>20 participants (11 men) Age range: Time since stroke: 9 months – 15 years</p>	<p>Observations of activities and interactions</p> <p>Ethnography</p> <p>Caregivers were involved as a part of the ethnography and gave interviews based on the experiences of</p>	3 observations of participants	<p>Interpersonal exclusion</p> <p>Identity and personhood</p>	9

					the person with aphasia			
25 HQ	Pringle, Drummond & McLafferty (2013)	UK	Improve understanding of the experiences of patients and carers during first month at home after discharge from hospital after stroke	<p>12 patient/carer dyads (7 male stroke survivors)</p> <p>Age range of survivors: 47 – 82 years</p> <p>Time since stroke: at least one week.</p>	<p>Semi-structured interviews (at 1 month post-discharge) and self-report diaries (for one month after discharge)</p> <p>Interviews with people with communication difficulties were aided by picture aids</p> <p>IPA</p>	22 interviews carried out - separate for stroke survivors and caregivers	<p>Revisioning</p> <p>Reconnecting</p>	8.5

Appendix C: CLR Second Order Constructs Table⁷

	Second Order Constructs	Description	My notes
Anderson (2012)	- depersonalising interactions and feelings of inferiority – <i>“you get treated like an idiot once you had a stroke. You are ignored as a person... you fell off the face of the earth”</i>	Constant negotiation about whether they can complete an activity – vulnerable to how they were treated and <i>positioned</i> by other people. Could position themselves in one way but this could be undermined by others by talking down to them	Other people’s views of yourself diminishes your identity – others responses interact with how you view yourself.
	- friends avoid relationships with you	Role of physical and cognitive impairments getting in the way	
	- stigma of disability is like losing a reputation <i>“not everybody sees you as a person with something to give... they are going to look at one part of you, and that’s the damaged frail part, too frail to have a relationship with”</i>	others have stereotyped ideas about capabilities of person with disability and this affects their interaction and relationship with you it’s very difficult to get your reputation back.	
Boylestein (2007)	Losing the battle means losing your identity – constructed identity depends on being victorious? <i>“I’ve always been a fighter”</i>	Not achieving the personal aims set in recovery can be seen as a destruction of self-identity	The struggle against accepting a new identity, or an illness identity.
	What is a man?	The role of gender, and a stroke questioning the very essence of being a man because you cannot do the same things	Pushing to achieve something, don’t achieve, lose identity – depression
	Not regaining the victory – loses the battle, results in depression	Losing the fight with your own body and still wanting things that haven’t been achieved can result in depression	
Burton (2000)	Changing roles	Roles and responsibilities are threatened – work, finance, family and social networks	Stroke colours view of future life and what one may ‘be’ or ‘achieve’
	Re-appraisal of social roles	Unable to do the same thing anymore and struggling to accept this	
	Stroke impacts future life	Stroke impacts having a ‘normal’ future and changes plans	
	Comparison to pre-stroke life – new life	Negative downward social comparison based on their pre-stroke self	Pre-stroke self compared to

⁷ Quotes from papers in quotation marks, in italics

	unfamiliar <i>"it's not the same"</i>		current self
Clarke et al (2005)	No longer the same person I used to be <i>"I cannot relate back to where I was before I had the stroke. I just can't get it through my head to let that go, I can't do that"</i>	This was related in the text to physical activity and not being able to do these things and therefore they cannot see themselves as the same person anymore	Pre-stroke self
	Self-defining activities were integral foundations of pre-stroke life	If 'self-defining' activities were impacted by the stroke this changed quality of life and people's views of themselves as a person	Roles impacting sense of self – difference in valued roles and whether they are impacted after stroke affects maintenance of sense of self
	Able to maintain valued roles not affected by stroke – sense of self remains intact	If identity did not hinge on physical or cognitive independence, they quality of life was less affected and continued to view themselves as the same person	What is it about these self-defining activities that are so important? Eg, to be a physically active person
Crowe et al (2015)	Pre-stroke self contradicts post-stroke self	<i>A lament</i> of for the pre-stroke self and <i>rejection</i> of post-stroke self	Struggle to be the same person
	The stroke TAKES a core sense of identity <i>"I'm not the same person"</i>	Loss of formed activities, lifestyles and roles – resulting in a struggle to forge a new sense of identity. Loss of a sense of self, loss of former coping strategies	Stripped of sense of self
	Post-stroke self is rejected <i>To resume right where I left off</i> - Underlying this was a lack of self-compassion for post-stroke self	Recovery was about a return to pre-stroke selves, resulting in a rejection of post-stroke self - Underlying this was criticism and a lack of self-compassions	Why does loss of activity and role affect identity???
	Role of self-compassion	Self-compassion was fundamental to accept changes associated with stroke and the post-stroke self	Role of acceptance of new self vs. struggle of pushing away new identity
Erikson et al (2010)	Discrepancy between past and present life	<i>It's obvious, like before you were somebody. I mean both in private and professionally. Then suddenly you are nothing, just a person in your bed</i>	Invisible difficulties cause further problems in alienation in social circles
	Dependency on others	<i>I decided everything by myself and now others decide for me</i> Others have to be involved with you to be able to function in society	Unable to exist as a human being on your own – got to rely on others – therefore not
	Invisible difficulties means people don't recognise things and this is alienating	Others demonstrate a lack of recognition for a decrease in contributions because of invisible difficulties	

			a whole person
Erikson et al (2009).	Passage of time after stroke affects development of new self	It's harder at first to accept who you are, and over time you know what to accept and what to fight for	New ways of doing valued activities – continuation of sense of self Not fighting against old self and acceptance of changes
	Being 'altered' by the stroke	Negative feelings associated by being changed by the stroke, need to search for a new self	
	Finding new ways of 'doing' to develop sense of self	Searched for a new self by finding new ways of doing/ re-appraising occupations to narrow the gaps	
	Role changes in family affect sense of self	This can have a positive effect as well – finding new ways of relating to one another. <i>They same I'm a 'second coming' of Eric</i> understanding and enjoying being interdependent in relationships	
Fallahpour et al (2013)	Not being able to do anything alone	Go from <i>doing nothing alone</i> – to – doing something, but making it happen differently. It means a lot to not be able to do anything alone and experienced negatively. A loss of daily routine upset how ones sees daily life, and therefore themselves – loss of daily routine created significant loss in daily life	Labels and language " <i>I am... I was.... I am not....</i> " Gender stereotypes (culture? – is this me being biased?!) Roles of others views interacting with view of themselves Role of occupational identity – primary expression of self
	Being an 'object' not a subject " <i>piece of meat present there</i> "	The loss of being a subject able to act and decide in order to experience engagement, rather than being an object. Being an object meant they couldn't make their own choices and to be the centre of their own worlds. depends on behaviour of family – not being listened to	
	Others responses after stroke affect sense of self – <i>other people treat me like an object</i>	Discover a different self through communication with others. When people treat them with respect and allow them to make their own decisions this is experienced differently. When treated like an object this felt like they were stripped of who they are.	
	Role of gender	Valued life roles influenced the way they viewed themselves – value within the family. Different genders experienced different types of losses but both affected sense of self	
	Comparison to former self and roles previously performed <i>I worked, I did, I cooked, I invited, I went to, I could... but now I can't do anything</i>	<i>That self doesn't exist anymore</i> The greater the gaps in doing, the greater the experience of differences between pre- and post-stroke self <i>I want to be who I was before</i>	

	Total loss of self <i>doesn't exist anymore</i>	<i>From other people's point of view, I do not exist. They asked for my views before when they wanted to do something, but now it's not the same. It feels like I don't exist as a person, not at all</i> discovery of a different type of self through communication with others	
	Meaningful activities protect sense of self	Being able to have meaningful activities protects ones self-identity	
Gallagher (2011)	<i>Being Less</i>	Being less than 100% - a change in personality identity rooted in physical changes that prevent survivors from carrying out activities that they see as self-defining <i>you are conscious enough to know something is being taken away from you</i>	Being less in eyes of self – where does this view of being less come from? Socially defined about what people should contribute to society?
	Personal identity inextricably linked to doing things – self-defining activities	Functional losses have a big impact on how a stroke survivor views themselves <i>Being normal</i> is being the same person they were before the stroke	
	Prioritising skills important to regaining identity	<i>Making the list</i> and naming was skills are important for personal identity and then prioritising these – this also involves a tallying of losses that need to be overcome to regain identity and <i>become normal</i>	
Horne et al (2014)	Having a stroke questions who you are	Skill loss, decreased competence, lack of engagement in activities described as contributing to a feeling of being a lesser person	Catastrophic stroke event – start to build identity all over again
	Pre-stroke self comparison	Compared current self to how they were before, and this was a more confident person <i>'m just a totally different person</i>	
	Being a (insert role)	ROLE LABELS are lost and make a feeling of being a lesser person	Identity hangs on attributes 'being a....' – global thinking – then become nothing
	Regain skills/habits – redefine identity	Being successful in regaining skills and habits and routines helped redefine identity	
	Negative judgement from others impacts ability to think about self	Negative judgement from other undermines their ability to think positive about themselves, resulting in being anxious and uncomfortable in social situations. Avoidance behaviours were then evidence. A combination between how one feels about oneself and the feedback we receive from others	What constitutes being a person??
Kitzmuller (2012)	Being treated like a child	Not being treated like an adult was a wounding experiences	Maintaining social roles difficult based on other peoples responses
	Overlooked in society <i>"people changed their direction"</i>	<i>Sitting in a wheelchair I knew people changed their direction.... The way they look at you... you can nearly read their thoughts</i>	

		Perception of post-stroke body as <i>not me</i> was reinforced by the gazes and negative reactions of others	Value as a human being in roles Labels – vegetable Acceptance vs. struggle with being new person
	Old friendships harder to maintain than new friendships	Strangers often showed them more respect than friends and acquaintances, easier to establish new friendships than re-establish former social contacts	
	Losing profession – “ <i>you haven’t as much value as before</i> ”	Toughest for those with good jobs and higher education. Losing a job also meant losing networks and <i>belonging</i> Produced feelings of worthlessness and low self-esteem	
	Gender roles	The roles they missed depended on gender roles. Housewife, grandmothers, mothers... driving the car, painting the house....	
	Accept disability and integrate into sense of self	Grieving losses participants gradually learned to accept disabilities and integrate them into self-concept Positive contribution from peers was essential for this endeavour – sharing similar experiences and support	
	Communication difficulties affect identity “ <i>feeling like a vegetable</i> ”	Struggling to communicate resulted in a big change in identity and being unable to feel ‘normal’	
	Negative perceptions of self - grief	Grieving for who they used to be	
Kouwenhoven (2011)	“ <i>being someone</i> ” - “ <i>I’m characterised more by the things I can’t do</i> ”	Not being the one they know and could count on leading to a feeling of failing. Being able to cope with different tasks and situations was the same as ‘being someone’	Role of labels again Regression into child like state, interacts with how other people treat them Feeling of emptiness/searching for identity Patient/dependant identity Do = identity – roles in society
	Becoming a child again	Not being able to do anything at all felt like being a child again.	
	“ <i>highly dependent patient</i> ”	Holding a new identity of being highly dependent patient compared to being an <i>independent strong man</i>	
	“ <i>I am nothing</i> ”	Having a stroke made them feel like <i>nothing</i>	
Kuluski et al (2014)	Sudden loss of former self “ <i>stole a part of me</i> ” “ <i>that woman had died, the one that</i>	Having a stroke completely changes life beyond recognition and strips people of being themselves	Withdrawing from society based on what other people

	wore high heels and walked around and ran a business..."		might think
	Childlike life	<i>A baby with an adult mind</i> complete change of day to day functioning and unable to do these things themselves feels like unable to be an adult	Building a new identity and starting again – but finding ways to continue old self
	Activities are integral to self	Particularly for active people with dual-responsibilities (caregiving, working), losing activities and the ability to perform was taken away by the stroke, and threatened their sense of identity	Accepting – not fighting
	Not socialising as much – remind them of former self and how other people would view them <i>"not as fun... self-centred"</i>	Distancing themselves from social relationships and outings because it was a reminder of their former self. Worried that others would perceive them differently because they were not able to engage in meaningful, ongoing conversation in the same way.	Labels....
	Becoming a new person <i>cut off all my hair</i>	<i>"I had long hair.... I had all my hair cut off. The hairdresser said 'are you sure about this?' I thought this hair is the hair of her, it's the hair of the women that could walk and well, you know, wasn't disabled and I don't want her hair anymore because I'm not her now. I'm somebody else"</i> having a stroke completely changes your identity and who you are... being disabled is a new you.	
	Finding new ways to do old activities and re-establish roles <i>"black piece of paper"</i>	Engaging in new ways with activities important to them before the stroke – finding a way to re-establish these roles <i>I sat down with a blank piece of paper and thought 'well, what do I want to do?' I knew I didn't want to stay at home the whole time... I knew I enjoyed meeting people and being part of a team.... I applied for something and I've been there ever since"</i>	
	Accepting dependence and not fighting	Accepting being dependant is an important thing to get over in your mind to be able to move forward, and to not fight against that need for help.	
	Gender roles	Having different gender roles impacted peoples sense of self	
Kvigne et al (2010)	Struggling to accept help – fighting this to maintain roles	Wanting to maintain the same roles as a housewife and not give over control to a carer or husband	Being treated like a human being by other people
	Need to 'renegotiate relationships'	A long-term disability may threaten the balance and quality of interpersonal relationships – need to renegotiate them to manage the change in role. Could result in becoming interdependent and still	Role of relationships – peers vs. healthy people important New ways of interacting with

		maintaining the relationship in a close and positive way	world and negotiating same identities through continuing roles Being disabled makes you UNEQUAL in society
	Friends helping vs. losing friends	Some friends continue to see the person in the same way and as the same person, and will integrate the disability into the life situation and acidity. Other friends fall away and struggle to integrate this	
	Making new friends	Opportunity to make new friends – friendships with other stroke survivors discussed the importance of a shared world and values.	
	Peer relationships vs. 'healthy people' -	Peer relationships important because of shared world and values. Being with healthy people might lead to alienation. Friendship with people who shared or understood their situation opened for relationships on EQUAL terms	
Martinsen et al (2012)	Transformation of identity to independent/active/participating person to dependency... <i>"I don't wish to have changed"</i>	Facing the shortcoming of being less able to care for others, less able to carry out normal tasks influenced their identity. <i>You get very dependent and simultaneously you don't want to be so dependent that others take your role" I wish to be the one I was. I wish to be myself</i> Having the involuntary role as a home worker was frustrating and uncomfortable for men and women.	Change in families – context of relationships and others not completely understanding the differences
	Not participating in society in the same way through judgement of others	Others talk about how they just stay at home and unable to participate in society as expected of them. Choosing to be self-protective and withdraw from society when this is a problem, and when people's invisible difficulties are not understood by others	Positive of building a new life
	Making a new life can be positive	Being able to prioritise and understand what is important in life.	Needing to protect yourself in social situations
	Pre-stroke ideals <i>"I am not able to be what I wished... a real grandma"</i>	Having things taken away like a thief in the night.	INVOLUNTARY DISABLED ROLE
Murray et al (2004)	<i>"loss of me"</i> Activities and skills so interwoven with sense of identity Multiple losses of cognitive and physical disabilities – profound loss of self	<i>Its hard struggling with the loss of me, especially the strong, capable and always caregiver me</i> Activities and skills which the pre-stroke self engaged in and lost following a stroke were so interwoven with participants sense of identity that still don't know who they are years later.	Activities KEY to identity How to make a new me in relation to world around me

	Distances from the new self “ <i>who the fuck are you?</i> ”	Their own personhood had a strangeness and unfamiliarity to the, <i>the person that I used to be is this far from me (uses arms to indicated distance) I am different, not the same person. I have looked in the mirror and said ‘who the fuck are you?’ – it looks like me but it isn’t</i>	Physical distance from being the same person – unrecognisable
Taule et al (2014)	Being <i>good enough</i> – own perceptions of close roles, professionally and personally	Less able of what was ‘normal’ pre-stroke and perception of how this complicated important relationships – not just about own perceptions but in relation to others. Maintaining old roles important but threatening. Longing to belong in work communities	Comparison Burden, disability identity Longing to belong
	Role of comparison to others <i>reduced stupid second division</i>	Compared themselves to others who have had stroke/others who haven’t – both affected sense of self negatively	Loss of social contact – conflict between withdrawing from social activities because couldn’t be the same person as being, and also missing social lives
	Role of needing help from others – <i>burden dependency parasite on my spouse</i> inferiority	Self-perception closely related to the feeling of needing help from others versus the feeling of being in control of a situation. Characterised by fear of being a burden at the mercy of others’ circumstances	Maintaining old roles was threatening
	Loss of conflict with friends and colleagues – conflict of choosing to withdraw and falling short of other people’s expectations	Participants opted out of social contact because presenting themselves in the same manner as before the stroke was too demanding, however they missed their social lives. Also feared what other people thought about them.	
	Communication difficulties – how other people perceive me	Very concerned about how other perceive them, affecting their sense of self. And self-esteem	
Thompson et al (2009)	Labels upon self <i>miserable pig, lazy, useless, nuisance, burden</i> , - in context of being dependant on spouse	Feelings of guilt, low self-esteem and despair as a result of how they felt about themselves in the context of needing help from others	Why do people put labels on themselves – in the context of fulfilling roles
	Gender roles <i>not as much of a man as I was before</i>	Role of gender and stereotyped gender roles are important in affecting sense of self after stroke <i>you’re not as much of a man as you were before</i>	Socially defined relationships and what that means a person should do.
Wolfenden (2012)	Fluid/changing identity – absorb stroke into my identity	A fluid, evolving sense of identity after stroke.	Fluidity of identity
	<i>Disability is not me... not the sum total of</i>	Resisted being defined by their stroke, seeing identity as a sense of self	What does it mean to be

	<i>me</i>	that transcends physical capabilities <i>'The thought process inside my head was disability is other people and disability isn't me. I'm not disabled and I'm not going to be disabled' 'that's not the sum total of me. That's not how I was identifying myself</i>	disabled in society – struggle against being a 'stroke survivor' SIT – holding a negative perception of stroke makes people not want to identify with that
	Identity re-establishment on values - protective	Easier to maintain sense of self and have a continuity of self if not relying on physicality. Values that can still continue after stroke – still the same me	
	Withdrawal from social situations as I'm different from the social norm	Feeling dislocated socially from friends her own age and therefore choosing to withdraw from social situations with friends because she's so different from them.	Role of withdrawal based on what other people might think
	Peer identity – don't identify with 'stroke'	Closer identification with people who are not significantly disabled means identifying with the stroke group is difficult <i>I don't feel comfortable going (to stroke support group) because I don't really think I fit the mould. I wouldn't want to make other people feel bad</i>	Fighting against that identity – coming from holding a negative perception of what it means to be disabled therefore fight against it
	Resuming life roles – identity re-establishment	Resumption of life roles and responsibilities contributed to identity re-establishment – familiar routines and activities – worker, friend. Willing to accept capabilities had changed, but determined to reclaim activities that were important to sense of identity <i>go back to really core things</i>	
CAREGIVER STUDIES			
Dowswell et al (2000)	'disabled' state as a source of shame in the light of post-stroke self	Perceived personality changes felt deeply by the patients and were uncomfortable with their current disabled states – and were ashamed of this, and did not want to burden friends/relatives with their post-stroke 'new self'	Disability label – what does it mean to be disabled in this society
	Making careful choices about social lives – loss of social networks	Clear deterioration of social lives of social lives. All discussed having some visitors, but didn't make visits themselves. More careful choices about their social lives, bringing about changes in relationships with family and friends <i>I found I was passing people I knew, and speaking to people I didn't know</i> Some social networks were maintained, others were lost.	Acceptance vs. struggle Social network changes

	“alphabet of feelings”	Angry ashamed overwhelmed burdensome depressed inadequate frustrated helpless imperfect, shocked, suicidal, tearful, surprised, vulnerable, worries....	
	Standard of measurement is pre-stroke life <i>“I’d like to be my old self”</i>	Measurement of recovery is against old self. Admitted to ambition and therefore dissatisfaction with the size of the gap between where they had reached and where they would like to be.	
	Struggle to accept disability <i>“this is not my life... this is not me”</i>	Major difficulties of adjustment – acceptance of continuing and the relatively permanent disability	
Ellis-Hill et al (2000)	<i>“half a person”</i>	Stroke takes away a fundamental part of yourself which you can’t get back	Half a person... stroke/disability diminished what it means to be a person Role of body and appearance vs. invisible difficulties. Body is a barrier in social situations
	No return to previous life... <i>“normal life one day...overnight comes to an end”</i>	Radical change and profound disruption to life <i>you lead a normal life one day, and within a matter of minutes overnight it all comes to an end - a sense of no return, not being able to get back to where I was before</i>	
	Role of invisible difficulties in social situations	People expecting too much - other people can be dismissive and not incorporate the invisible difficulties into the social situation	
	Having a ‘disability outlook’ in social situation	<i>Now my unconscious was dominated by a disability outlook and a fear of failure in the real world</i>	
	Body is the focus of social gaze <i>“I feel like a freak”</i>	In the house can be themselves, outside of the house, the body became the focus of social gaze and a barrier between relationships with others <i>I still feel like a freak</i> appearance paramount in social situations in the western world – adults lose control of their bodies is unacceptable <i>I feel like I’ve let the side down but having a stroke like that and certainly only half a person</i>	
Musser et al (2015)	Loss of employment, forced to retire	Each participant lost their employment role. Feeling of displacement being forced to retire.	Avoidance from friends in social situations – a stroke is CATCHING Being treated like a human rather than an object maintains social identity
	Acceptance or a struggle	Difficulty in accepting change to roles and trying hard to find new ways to fulfil those roles and needs Able to re-prioritise and find new ways of doing things, able to get in touch with being the same person as before	
	Shift in roles in relationships not always negative	Jointly negotiated with family, changes of dynamic of a relationship and a shift in balance of role	

	<i>"a stroke is catching"</i> – friends avoid situations	Some friends completely avoid the person as if reminded of own mortality <i>the thing I observed was I think men, it was very scary from them when he had the stroke. And they sort of avoided him for a while... you know, like it was catching or something</i>	
	Choosing to withdraw from social situations	Experienced changes in their sense of themselves in their broader social lives – levels of independence and ability to meet and talk to new people. Withdraw from social situations, enjoying them less because can't participate in the same way	
	Change in relationships	Some friends continue as normal, some disappear. Responses from others helped shape some of their new social identity. Contact in unexpected places and new friendships developed. Some responses from social circle helped re-affirm their social identity as valued in society	
Palleson (2014)	Loss of social relationships over 5 years, changes how people view themselves	Relationships with those closest to them were disrupted and social contacts diminished over 5 years – loss of capacity to work... loss of social circles. A major loss that was significant in how they viewed themselves	Disability, relationships and self-identity closely related
	Support from family and friends impacts self-perception	Continued support from family and friends maintains and upholds identity Autonomy was a central theme that affected self-perception Having fellowship and belonging and being treated like normal was important for recovery	
Parr (2007)	Friends fall away	People did not know how to communicate with them and seemed awkward or frightened, and friends fell away	Role of language in identity and being able to express yourself in social situations What does it mean to be a person in society that can't speak
	Being talked <i>about</i> rather than <i>to</i>	Communication strategies that were alienating to the person – string of single word commands, being talked about, teasing, insisting on repeated words and phrases, not acknowledging the person	
	Choosing to withdraw from social situations	Most patients chose to withdraw from social contacts and were unable to participate	
	Loss of personal history and depersonalisation in nursing homes	Constriction of plans and hopes, loss of personal histories and understanding of being a whole person particularly in places like nursing	

		homes	
	Perceived as less human without language	Treated as if you are 'not quite a person' – talked over, referred to... cannot communicate therefore seen as less than a person	
	Still seeing the human	Being absorbed as normal into communities and still being understood, patience to listen and understand, and be treated like a human being by others	
Pringle et al (2013)	infantilised	Blocked in development of progress	<p>Having a part of you taken away</p> <p>Being treated like a human being</p> <p>“belonging” in a social group retains value</p>
	Becoming a wholly different person	Even losing an educated identity as if this changes by having a stroke. Conveying a sense that a part of their identity as being taken away and replaced with an old man/disabled person <i>I want others to see me as perfect</i>	
	<i>Bringing things into focus</i>	New sense of focus on what matters in life and what to put energy into	
	Feeling valued by others	Being communicated with is important and when people make the effort – feel valued When other people make an effort to communicate Need to incorporate this into my identity <i>Being without a voice</i>	
	Turning towards, and turning against acceptance of new reality	Placing themselves within a new reality and adjusting to it	
	Having a sense of belonging	With family, social groups... being a part of something	
	Choice and control over seeking help vs. dependence		
	Comparison to others	Results in a judgement of their own progress.	

Appendix D: SIP Author Guidelines

Author Guidelines: *Archives of Suicide Research*

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Archives of Suicide Research, the official journal of the International Academy for Suicide Research, is an international journal in the field devoted to suicide research. The contributions in Archives represent the breadth of suicide erudition in the scientific community featuring original research from diverse disciplines including biology, psychiatry, psychology, and sociology. The journal has become renowned for reporting on the most current and relevant aspects of suicide research, as well as defining the foundations of the field.

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- Title of the manuscript: Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 characters and spaces.

- Total word count

-Up to 6 keywords (Please consult our guidance on keywords [here](#).)

- Complete contact information: this includes the corresponding author's full name, title, telephone number, fax number, and e-mail address.

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Abstract: Each article should be summarized in an abstract of no more than 120 words. Abstract should be separated into Objectives, Methods, Results, Conclusion. Avoid abbreviations, diagrams, and reference to the text.

Text: The contents of the text should adhere to the general structure of scientific papers: introduction, method, results, and discussion. If applicable, it should be made clear in the methods section that informed consent was obtained from subjects who participated in the study.

Illustrations: Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.) should be clean originals or digital files. Digital files are recommended for highest quality reproduction and should follow these guidelines: 300 dpi or higher; sized to fit on journal page; EPS, TIFF, or PSD format only; submitted as separate files, not embedded in text files.

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Tables and Figures

Tables and figures should be numbered and included as separate sheets or files. Tables and figures should not be embedded in the text. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double-spaced, on a separate sheet.

References

References should be listed on separate pages following the text. They should be listed alphabetically by first author and should not be numbered. Be sure all references have been cited in the text. Provide the last names and first initials of maximum three authors; "et al." should be used for articles containing more than three authors. Journal names should not be abbreviated. Italicize journal names and book titles. Article references should include the author names, year of publication, title of the article,

complete name of the journal, the volume and the page numbers in which the article appears.

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Appendix E: SIP Interview Schedule

Thank you for agreeing to take part in this focus group today. As you are aware, we are going to discuss suicidal ideation and attempts in older adults. You have all been invited to attend because you have worked with older adults in a mental health context for around 5 years or more, and I am interested in the experience you may have gained in this area. The information discussed today will be confidential, and I ask that you respect one another's opinions and responses. The discussion today is being recorded for research purposes only, and will be destroyed once it has been transcribed and anonymised. As there are a number of people in the room, it is important we take turns to contribute to the conversation, and this would also make transcribing easier!

Confidentiality will only be broken in exceptional circumstances if there are significant grounds for concern about a response given, and this would be discussed with you beforehand. You have the option to withdraw from the focus group throughout. We will ensure that individual participation will not be identifiable in any report generated from this focus group. As we all know, this is a sensitive topic, so please look after yourselves during this discussion.

During the discussions, I ask that you could bring to mind experiences of dealing with suicidal ideation and attempts in older adults in your clinical work. You do not need to discuss specific details of cases and I ask you do not do this today, anything related to a case must be anonymous. If you could, hold in mind your experiences and knowledge of this area to base our discussions on.

Do you have any questions about this before we begin?

- 1. Is working with suicidal ideation or suicide attempts something you have come across frequently in your work with older adults?**

Can you tell me more about this?

What, if any, are the common issues you might come across when managing suicidal ideation or attempts in older adults?

- 2. What, if anything, has your clinical experience taught you about the nature of suicidal ideation or suicidal behaviour in older adults?**

- 3. Is there anything in particular that you routinely look for in highlighting possible risk for suicide in older adults?**

Prompts: any particular behaviours, social situation, their clinical presentation, the language they use, their engagement.

Can you tell me more about this...

- 4. Anything you think has been particularly effective in helping you manage this clinically?**

Clinical judgement, peers, supervision, national suicide prevention guidelines, previous experience.

Can you tell me more about these in how they have been helpful?

- 5. What are the main approaches/skills that you use when working with suicidal ideation or behaviour with older adults?**

Prompts: team working, communication, risk assessment, talking to other services, engagement, medication, supervision
Can you tell me more about these... what have you found helpful about these approaches?

- 6. What, if anything, do you feel could aid your development and management in working with suicidal ideation and behaviour in older adults?**

Prompts: more support from direct team, more guidance from service/MH provider/government, more training?
Tell me a bit more about this... why do you think that would be helpful?

- 7. What, if anything, do you feel could contribute to improving practice in preventing suicidal ideation and behaviour in older adults?**

Prompts: more communication, more research, more guidelines....

Final question...

Is there anything else you would like to add, for example, have I missed something you thought would be useful to talk about regarding the topic?

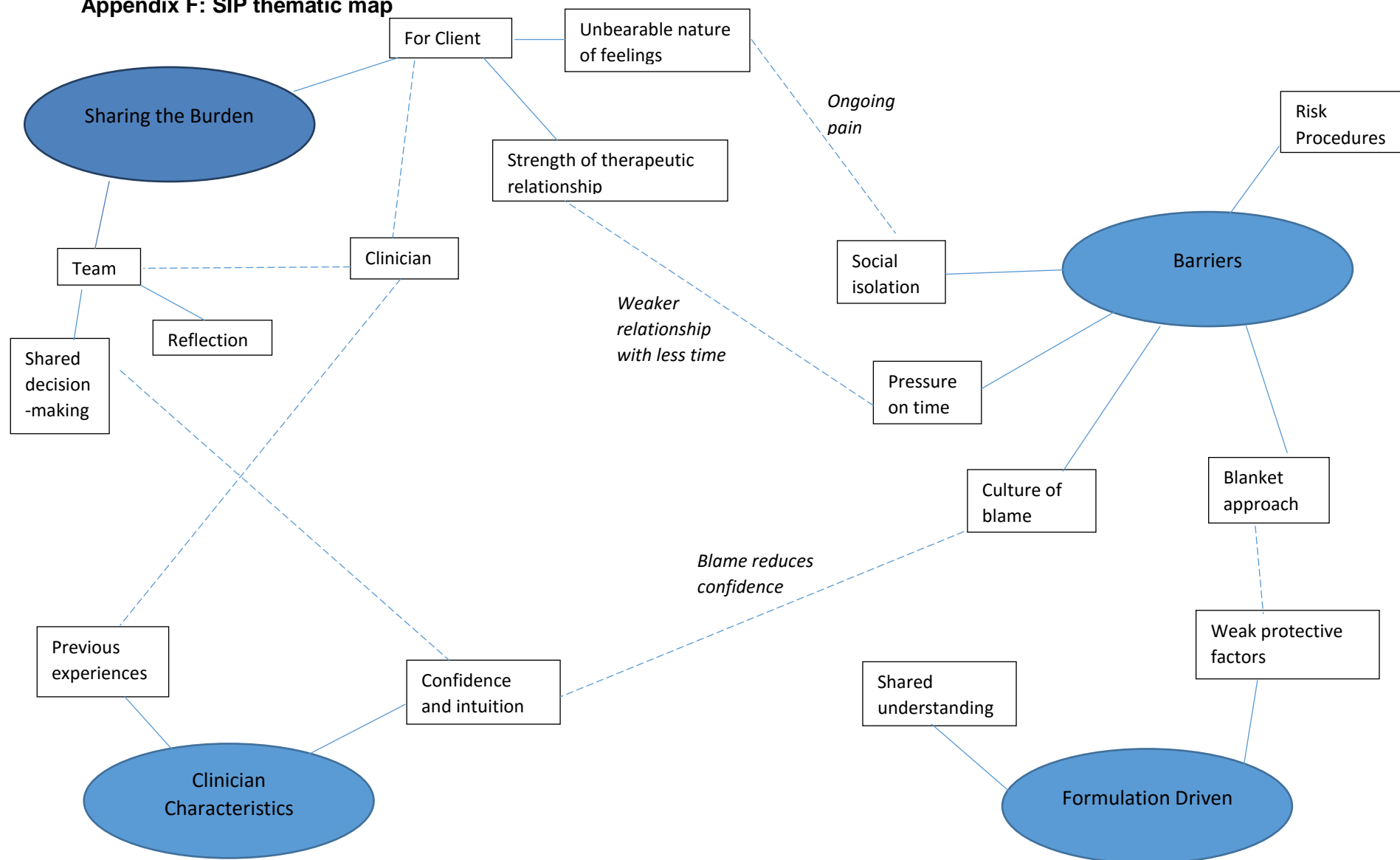
Secondary questions

How have you felt/do you feel, about managing suicidal ideation and behaviour in older adults, in your day to day work?

What do you find most difficult?

What, if anything, do you find rewarding about working with this client group in this situation

Appendix F: SIP thematic map



Appendix G: SIP recommendations

Recommendation 1	
Area of need	Peer Support
Issues raised	In the current context of change, participants felt time and space for peer support and reflection was neglected and not seen as necessary within the teams. Participants did feel this work was integral to their ability to work as older adult clinicians, and therefore felt time for peer support for older adult staff should be valued in the context of change to ageless services.
Recommendations	<p>Peer support is provided outside of team meeting space, with the aim of reflecting on the difficult nature of this work and discussions about sharing knowledge and improving confidence in working.</p> <p>Another focus of peer support could be to understand the role of developing therapeutic relationships with older adults, and how to develop skills in this to support effective risk management. This might involve staff learning sessions outside team meetings, where staff could share knowledge about developing effective therapeutic relationships and build on recent evidence-based practice.</p> <p>Co-work on resource-intensive clients with high risk to support staff. For example, if a staff member is finding one client takes up a large amount of their time and is finding this work difficult, co-working on this type of case has been found by our participants to reduce burden and increase effectiveness of working.</p>

Recommendation 2	
Area of need	Older Adult specific risk management approaches
Issues raised	Participants found taking a blanket approach to risk management difficult and restrictive for older adult client's recovery, and felt that because services have changed to ageless, the specificity of older adult risk management is not being developed within the trust.
Recommendations	The provision of complex case formulations where working with resource-intensive, high risk clients. This should be provided outside of team meeting space, and may be facilitated by psychologists from within the team. Additionally, a psychologist from outside the team could also facilitate such a meeting to enable a more objective look at the case.

	<p>Consultation with older adult clinicians about developing older adult specific risk information for the trust. This could be a specific piece of work which develops an 'older adult risk profile', paying attention to the differences between older adults and younger adults to be used within risk management approaches in older adult working. This could potentially be completed by a trainee clinical psychologist whilst on an older adult placement.</p> <p>Consultation process on older adult inpatient wards on risk management approaches to specify the difficulties in 'one-size-fits-all approach'</p> <p>A continuing focus on formulation-driven approaches, understanding the changing nature of protective factors in particular. This may include keeping 'risk management' on a team meeting agenda, focussing on formulation driven practice.</p>
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Recommendation 3	
Area of need	Focus on therapeutic relationship with older adult clients
Issues raised	Participants felt with time pressures within the trust, they are being asked to build these relationships in short time frames which are very difficult with this client group.
Recommendations	<p>Therapeutic alliance is monitored in therapy where clients are at high risk, through supervision. This may be achieved through a rating scale of therapeutic alliance, for example. A supervisor could also keep this item on the agenda, allowing for personal reflection within the individual clinician about the therapeutic alliance.</p> <p>The need for therapeutic relationship is reflected in care pathways – reduce the amount of clinicians needed at transition points, in particular. This point was raised with Dr Anthony Harrison and he was considering how to take this recommendation forward. For example, this may involve being aware of the difficulties with transition for older adult clients and increasing availability for contact at that point with a key worker.</p> <p>As a team, have an awareness of high risk clients who need more time and resources for clinical work. This may involve having a repeating item on the team meeting agenda for 'higher-risk' or resource-intensive clients, and allowing for repeated opportunities for these clinician's to seek support around these clients. This is particularly important as team's transition into more 'mobile working'.</p>

Recommendation 4	
Area of need	Working with a socially isolated client group
Issues raised	A continued difficulty for the participants is working with a client group who are socially isolated, with a sense that this social isolation can maintain a client's hopelessness and increase their suicidal thinking.
Recommendations	<p>Within the ageless teams, need to be mindful of the older adult specific voluntary sector. Ageless teams need to be able to understand the specific voluntary organisations available for their older adult clients, and share this knowledge within the teams. It may be that older adult clinician's take a lead of this within the teams.</p> <p>A review into the links with voluntary sector for older adult clients, and how to improve key services within the area, with clear communication and referral links. This may be an appropriate consultation project for a trainee clinical psychologist.</p>

Recommendation 5	
Area of need	Perceived blame
Issues raised	Participants felt that even though the RCA process is non-blaming, blame can still be felt individually
Recommendations	<p>Staff continue to be supported within supervision when going through an RCA. The issue of feeling blame should be recognised and discussed in supervision and its potential impact on future work. This may involve support from within the team (i.e., their supervisor, or independent senior member of the team), or the staff member could also be made aware of support from the wider trust from occupational health.</p> <p>Debriefs and support for a team when a serious incident has occurred and the team are going through an RCA.</p>

Appendix H: SIP Ethical Approval

FW: service evaluation project

[Brandling Janet \(AVON AND WILTSHIRE MENTAL HEALTH PARTNERSHIP NHS TRUST\)](#)

You replied on 03/11/2014 12:35.

Sent:03 November 2014 12:20

To: [Knight Rose \(AVON AND WILTSHIRE MENTAL HEALTH PARTNERSHIP NHS TRUST\)](#)

Dear Rose

This looks an interesting project and I am happy to provide approval based on the following amendments and sight of the university ethical approval document.

As you will know research and evaluation require different governance arrangements. You need to be clear about whether you are conducting research or service improvement with an evaluation component. As such you need to be consistent in your terminology. I suspect that in borrowing from the research world your consent form and information sheet use the research terminology and this can be confusing for the staff/people engaged in the discussions and for the governance process. Can I suggest you make changes so that it is clear to all concerned that this is not research?

I enclose approval subject to these changes and the checklist document.

Dr Janet Brandling
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Email: janet.brandling@nhs.net
<http://ourspace/Skills/Academy/Pages/Home.aspx>
Please note: I do not usually work on Fridays

To whom it may concern,

I am a Clinical Psychologist in training with the University of Bath. I would like to conduct my service evaluation project within AWP, more specifically older adult services. I am looking into the management of suicidal thoughts and prevention of suicidal action in older adult services, the only people involved will be staff members (no patients). The aim is broadly to understand current practice and make recommendations for enhancing practice.

This project has been given ethical approval from the university and does not need NHS ethics, and has backing from Anthony Harrison, Suicide Prevention Lead within AWP. I can forward to you my ethics documents and proposal from the university if this might be helpful for you to help understand how I might be going about this.

Thank you
Best Wishes

Rose Knight
Clinical Psychologist in Training

Reference Number 14-183

The ethics committee have considered your ethics proposal for the study entitled 'Investigating staff members' experiences of the management of suicidal thoughts and attempts in older adults' and have given it full ethical approval.

Best wishes with your research.

Yours sincerely

--

Dr Helen Lucey
Chair Psychology Ethics Committee
University of Bath

Appendix I: MRP Author guidelines

Author Guidelines: Behaviour Research and Therapy

Introduction

The major focus of *Behaviour Research and Therapy* is an experimental psychopathology approach to understanding emotional and behavioral disorders and their prevention and treatment, using cognitive, behavioral, and psychophysiological (including neural) methods and models. This includes laboratory-based experimental studies with healthy, at risk and subclinical individuals that inform clinical application as well as studies with clinically severe samples. The following types of submissions are encouraged: theoretical reviews of mechanisms that contribute to psychopathology and that offer new treatment targets; tests of novel, mechanistically focused psychological interventions, especially ones that include theory-driven or experimentally-derived predictors, moderators and mediators; and innovations in dissemination and implementation of evidence-based practices into clinical practice in psychology and associated fields, especially those that target underlying mechanisms or focus on novel approaches to treatment delivery. In addition to traditional psychological disorders, the scope of the journal includes behavioural medicine (e.g., chronic pain). The journal will not consider manuscripts dealing primarily with measurement, psychometric analyses, and personality assessment.

Role of the funding source

You are requested to identify who provided financial support for the conduct of the research and/or preparation of the article and to briefly describe the role of the sponsor(s), if any, in study design; in the collection, analysis and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

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If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

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- **Title.** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.
- **Author names and affiliations.** Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.
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A concise and factual abstract is required with a maximum length of 200 words. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract itself.

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Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.

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Highlights are mandatory for this journal. They consist of a short collection of bullet points that convey the core findings of the article and should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point). You can view example Highlights on our information site.

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Immediately after the abstract, provide a maximum of 6 keywords, to be chosen from the APA list of index descriptors. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, please include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules.

References

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Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

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List: references should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

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Supplementary material can support and enhance your scientific research. Supplementary files offer the author additional possibilities to publish supporting applications, high-resolution images, background datasets, sound clips and more. Please note that such items are published online exactly as they are submitted; there is no typesetting involved (supplementary data supplied as an Excel file or as a PowerPoint slide will appear as such online). Please submit the material together with the article and supply a concise and descriptive caption for each file. If you wish to make any changes to supplementary data during any stage of the process, then please make sure to provide an updated file, and do not annotate any corrections on a previous version. Please also make sure to switch off the 'Track Changes' option in any Microsoft Office files as these will appear in the published supplementary file(s). For more detailed instructions please visit our artwork instruction pages.

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This journal enables you to show an Interactive Plot with your article by simply submitting a data file.

Submission checklist

The following list will be useful during the final checking of an article prior to sending it to the journal for review. Please consult this Guide for Authors for further details of any item.

Ensure that the following items are present:

One author has been designated as the corresponding author with contact details:

- E-mail address
- Full postal address

All necessary files have been uploaded, and contain:

- Keywords
- All figure captions
- All tables (including title, description, footnotes)

Further considerations

- Manuscript has been 'spell-checked' and 'grammar-checked'
- References are in the correct format for this journal
- All references mentioned in the Reference list are cited in the text, and vice versa
- Permission has been obtained for use of copyrighted material from other sources (including the Internet)

Printed version of figures (if applicable) in color or black-and-white

- Indicate clearly whether or not color or black-and-white in print is required.

Appendix J: MRP Intrusive Imagery Interview

Intrusive image interview

I'd like you to take a moment and think about the last time you were feeling really good. You might have felt quite excited or hyper, you might have had some great news. You might have had lots of thoughts and lots of energy, feeling like you could achieve a lot. The more you do, the more you feel you can do.

(ask participant for a word they use to describe this state and use this for the following question)

I'm going to ask you a number of questions about this time, so please could you bring to mind this specific time when that happened. *(? For non-clinical, need to ask what had happened to make the specific time more salient, get more data.)*

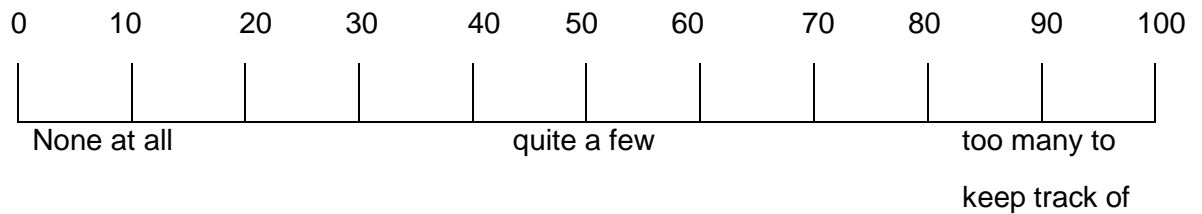
1. How long ago was this?

2. How long were you in that mood state for approximately?

I'm going to ask you some questions now about whether you might experience images, which take the form of pictures or scenes like a film in your head. This is the experience of 'seeing in your mind's eye'. For example, scenes from a holiday might randomly come into your head, or images of a parent or partner. This can range from a very fleeting, hazy picture, to a very clear and real image.

3. When you felt like this did you experience images, or pictures or visions in your minds' eye about things that could happen in the future? *(you might have elaborated in your mind things you could do, what could happen as a result of this time.... ? as a prime?)*

4. How many different spontaneous images/visions would you say that you experienced when you feel like that?



5. Would you say experiencing images in this way is typical for you when feeling hypomanic?

6. Do you experience the same, recurrent images/visions when feeling this way (*hypomanic*)?

Yes/No

7. If no, do you experience lots of different types of images and visions when feeling this way (*hypomaniac*)?

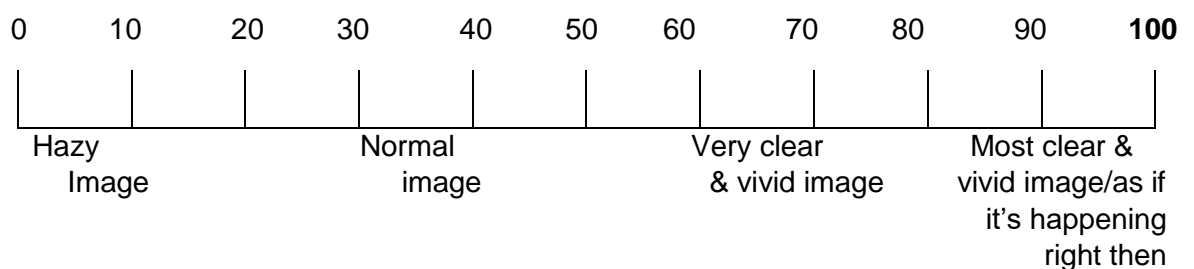
8. Do you have these same types images/visions when you feel

.... euthymic – yes/no

.... depressed – yes/no

9. Is there a particular example of such an image or vision that you might have when feeling hypomanic that you can think of now? Can you describe it for me?

10. Please rate how vivid/clear the imagery/visions are when you're feeling like that?



Image

11. How long do the images/visions last for? (seconds, minutes, hours etc)

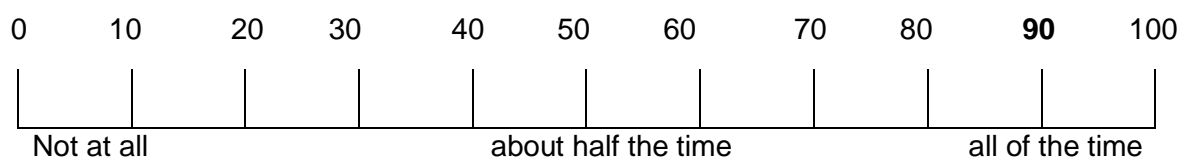
12. Do the images/visions spark off other images/visions or thoughts in your mind?

Yes

No

Can you describe the experience a little please?

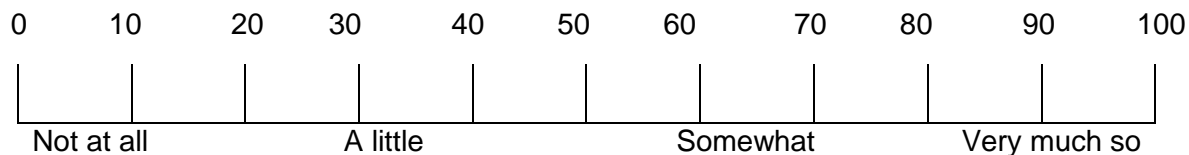
13. How much did the images/visions interfere with your daily life during the time that you were feeling....? e.g. would you not get something else done because of the effect of the image? Does it stop you from doing things?



I'd now like to ask you to rate some aspects of that image if that's ok with you?

Emotion

14. What kind emotions do you associate with the image/vision when you're feeling like that? how intense are they?



Sad=

Euphoric=

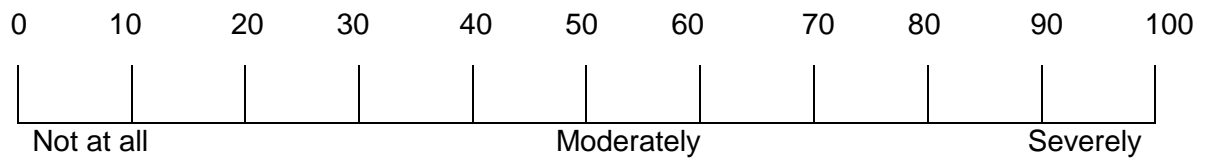
Helpless=

Powerful=

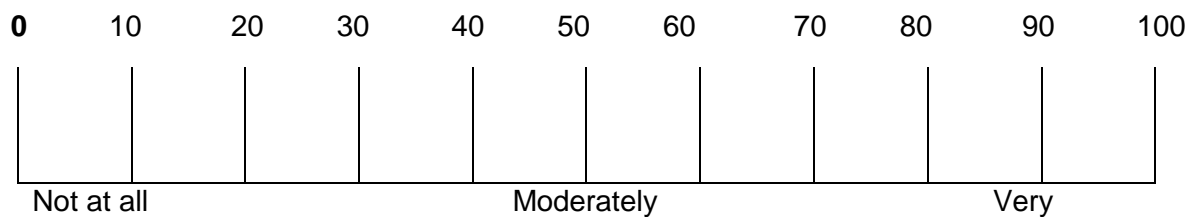
Anxious=

Fearless=

15. How distressing is your experience intrusive images/visions such as the one in the example?



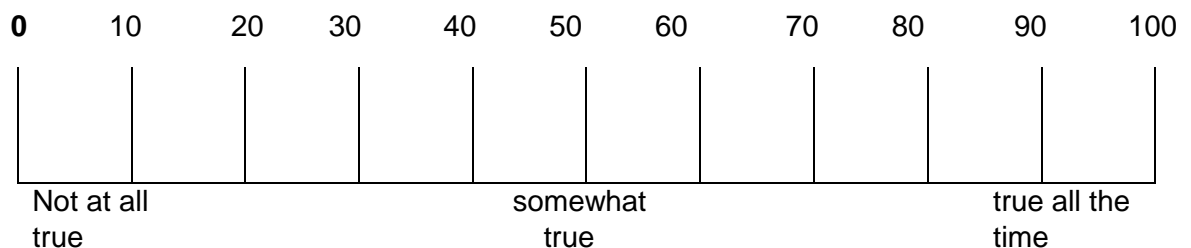
16. How enjoyable is your experience of intrusive images/visions such as the one in the example?



Responding to imagery

I'm now going to mention some specific things that people might do when experiencing imagery etc, some of which you might have mentioned but I'd like to get a rating for it.

17. When you have that image/vision, what do you do, if anything, in response to it?



- I just see it as a picture that has no meaning=
- I get sucked into the image and think about it more and more=
- I elaborate on the image in my mind and think about it more=
- I think about possible positive things that could happen because of the image=
- I think about possible negative things that could happen because of the image=
- I start doing lots of things=
- I make sure I keep a routine=
- I get lots of sleep=

What do you do when the images/visions pop into your mind when you're feeling.....?
(Response to Intrusions Questionnaire)

1.	I try to push the images out of my mind.	Never	Sometimes	Often	Always
2.	I try to erase the images from my mind	Never	Sometimes	Often	Always
3.	I try hard to control my emotions.	Never	Sometimes	Often	Always
4.	I distract myself with something else.	Never	Sometimes	Often	Always
5.	I think of something else.	Never	Sometimes	Often	Always
6.	I work hard at keeping busy with other things.	Never	Sometimes	Often	Always
7.	I think about how life would be different if the image was true.	Never	Sometimes	Often	Always
8.	I dwell on how what happens if the images could be prevented	Never	Sometimes	Often	Always
9.	I think about why the images happen to me	Never	Sometimes	Often	Always
10.	I dwell on how I could be if the images came true?	Never	Sometimes	Often	Always
11.	I dwell on what other people could do to me if the images came true??	Never	Sometimes	Often	Always
12.	I dwell on what I could do differently if the images came true	Never	Sometimes	Often	Always
13.	I go over the images again and again	Never	Sometimes	Often	Always
14.	I worry that something would happen to me or my family	Never	Sometimes	Often	Always
15.	I detach myself from the image	Never	Sometimes	Often	Always
16.	I drift off into a world of my own.	Never	Sometimes	Often	Always
17.	I numb my feelings.	Never	Sometimes	Often	Always
18.	I drink alcohol, take medication or use drugs.	Never	Sometimes	Often	Always
19.	I put on loud music or TV.	Never	Sometimes	Often	Always

Response to Positive Affect Scale (RPA)

Think about the images, or visions, we discussed when you are in that mood state. People think and do many things when they see images, or visions. Please read each of the following items and indicate whether you never, sometimes, often, or always think or do each one when you see an image, or vision about the future. Please indicate what you generally *do*, **not** what you *think you should do*.

1	2	3	4
Almost never	Sometimes	Often	Almost always

When you see the images/visions, how often do you...

- 1) ...notice how you feel full of energy.
- 2) ...savour this moment.
- 3) ...think "I am getting everything done."
- 4) ...think about how you feel up for doing everything.
- 5) ...think "I am living up to my potential."
- 6) ...think "This is too good to be true."
- 7) ...think about how happy you feel.
- 8) ...think about how strong you feel.
- 9) ...think about things that could go wrong.
- 10) ...remind yourself that these feelings won't last.
- 11) ...think "People will think I am bragging."
- 12) ...think about how hard it is to concentrate.
- 13) ...think "I am achieving everything."
- 14) ...think "I don't deserve this."
- 15) ...think "My streak of luck is going to end soon."
- 16) ...think about how proud you are of yourself.
- 17) ...think about the things that have not gone well for you.

Thank you for answering these questions. I just have a few more about your experience of these images.

1. When experiencing images/visions, how much do you think they representation you achieving future goals?
2. At the time how much do you think these images mean you will achieve your goals?
3. Looking back now at your experiences of the imagery, do you think that that they did help you achieve your goals?

Appendix K: MRP iHAPPI

Please read each of the statements below and make a rating in the right hand column to indicate how much you believe each one. Make your rating by intersecting the line between 0% (don't believe this at all) to 100% (believe this completely). For example 50% means that the statement is 50:50, equally likely to be true or false for you. Here is an example:

EXAMPLE:		
I feel comfortable in my home	0	50
		100
<p><i>This would mean that you rate your belief that you feel comfortable in your home at 70% - it is not completely true (which would be 100%), but is more true than false for you (i.e. it is over 50%).</i></p>		

Please now make a rating for each of the following items. Try not to think too much about each item. There are no right or wrong answers to this questionnaire and only your own opinion counts.

Please consider the images we discussed and ones like these that you might experience when feeling high and rate the following statements in relation to these.

		I DON'T BELIEVE THIS AT ALL	I BELIEVE THIS COM PLETELY
1	When I experience the imagery I feel good, and I am sure that everything will work out perfectly	0	50
			100
2	When I experience the imagery, I get excited, and feel I have no control over my thoughts	0	50
			100
3	When I experience the imagery, I get excited, and my fears and worries are no longer real	0	50
			100
4	When I experience the imagery I feel other people should admire me	0	50
			100
5	When I experience the imagery, my energy levels increase, and I believe I could bring about a large rise in my social status	0	50
			100
6	When I experience the imagery, I feel agitated and restless, and it means that I am about to have a breakdown	0	50
			100

Appendix L: MRP original HAPPI analysis

A mixed model ANOVA was conducted to understand the difference between groups of the amount of extreme positive and negative appraisals. There was a significant main effect of bipolar diagnosis ($F(1,34)=8.33$, $p=0.007$). This means there was a significant difference between the way bipolar participants endorsed positive and negative appraisals of an image compared to controls. There was a significant interaction effect between group and positive and negative appraisals ($F(1,34)=9.78$, $p=0.004$). Specifically, bipolar participants endorsed more positive appraisals (mean=51.82, SD=18.71) than controls (mean=44.92, SD=14.98). Bipolar participants endorsed more negative appraisals (mean=42.78, SD=16.51) than controls (mean=21.18 SD=14.61).

Post-hoc independent t-tests revealed that there was no significant difference between bipolar participants and controls with positive appraisals ($t(34)= -1.21$, $p=0.234$). Bipolar participants endorsed significantly more negative appraisals than controls ($t(34)= -4.13$, $p<0.001$).

Appendix M: MRP Ethical approval letter



London - Camberwell St Giles Research Ethics Committee

Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT
Telephone: 01173421330
18 September 2015

Miss Rose Knight
University of Bath
Claverton Down Road
Bath
BA2 7AY

Dear Miss Knight

Study title:	Investigating intrusive imagery, appraisals and positive mood states in Bipolar Disorder.
REC reference:	15/LO/1336
IRAS project ID:	162992

Thank you for your letter of 17 September 2015, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair. We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Gemma Oakes, nrescommittee.london-camberwellstgiles@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows: <i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Research Advertisements]	1.0	21 May 2015
Covering letter on headed paper [Covering Letter]	1.0	21 May 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of sponsor insurance]	1.0	21 May 2015
Interview schedules or topic guides for participants [Interview Schedule]	1.0	21 May 2015
Interview schedules or topic guides for participants [Structured Clinical Interview for DSM Disorders]	1.0	21 May 2015
IRAS Checklist XML [Checklist_17092015]	17 September 2015	
Letter from sponsor [Sponsor letter of support 7July15]	1.0	07 July 2015
Non-validated questionnaire [Verbal and Visual Intrusion Questionnaires]	1.0	21 May 2015
Non-validated questionnaire [Modified HAPPI - images]	1.0	21 May 2015
Other [Participant Debrief]	1.0	21 May 2015
Other [Cover Letter in Response to Comments and Provisional Opinion]	1.0	17 September 2015
Other [Participant Information Sheet - controls]	1.0	04 September 2015
Other [Questionnaire Cover Sheet]	1.0	04 September 2015
Participant consent form [Participant Consent Form]	1.1	04 September 2015
Participant information sheet (PIS) [Participant Information Sheet - bipolar participants]	1.1	04 September 2015
REC Application Form [REC_Form_16072015]	16 July 2015	
Research protocol or project proposal [Study Protocol]	1.0	21 May 2015
Summary CV for Chief Investigator (CI) [Rose Knight CV]	1.0	21 May 2015
Summary CV for supervisor (student research) [James Gregory Supervisor CV]	1.0	21 May 2015
Validated questionnaire [Beck Depression Inventory]	1.0	21 May 2015
Validated questionnaire [Hypomanic Attitudes and Positive Predictions Inventory]	1.0	21 May 2015
Validated questionnaire [Internal States Scale]	1.0	21 May 2015
Validated questionnaire [Spontaneous Use of Imagery Questionnaire]	1.0	21 May 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- ☐ Notifying substantial amendments
- ☐ Adding new sites and investigators
- ☐ Notification of serious breaches of the protocol
- ☐ Progress and safety reports
- ☐ Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the li

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/LO/1336 Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely



Mr John Richardson
Chair

Email: nrescommittee.london-camberwellstgiles@nhs.net

Enclosures: “After ethical review – guidance for researchers”

[SL-AR2] Copy to:

*Professor Jane Millar, University of Bath
Ms Marie Norton, Avon and Wiltshire
Mental Health Mental Health Partnership
NHS Trust*